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BOOK OF ABSTRACTS

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University Rehabilitation Institute Republic of Slovenia


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WELCOME ADDRESS

Dear Colleagues and Friends!

On behalf of the Scientific and Organizing committee of the 35th European Academy of Childhood Disability (EACD) Annual Meeting, it is a privilege and great pleasure to welcome you to Ljubljana, from May 24th to 27th 2023.

I would like to thank you for giving us the opportunity to hoste this event. Following the outstanding line of previous EACD annual meetings, we will do our best in offering an excellent opportunity to share experiences, exchange scientific ideas, and foster interactions between all professionals, children and their families.

The motto of this EACD annual meeting is "Smarter Goals for Better Future", with the intent to emphasize the importance of goal setting in all processes of care in the rehabilitation of children and youth.

Further, it is a great pleasure to announce a number of excellent keynotes with prestigious professionals in the field of childhood-onset disability.

Slovenia, your host country, tells its green story. Everything is green no matter which direction you turn – towards the Alpine peaks and extensive forests, the Adriatic Sea, the mysterious Karst and nearby vineyards, and the Pannonian Plain. Ljubljana

Ljubljana, the capital city, is a vibrant city with thousands of years of history. The European Green Capital 2016 has in a short time become a model of livability and eco-sustainability for all medium-sized cities in Europe. Our conference venue is in the city center, which is closed to traffic.

On behalf of the European Academy of Childhood Disability – EACD and University Rehabilitation Institute Republic of Slovenia, we look forward to welcoming you to the 35th EACD Conference!

Yours faithfully,

Asist. prof. Katja Groleger Sršen, MD, PhD

President of the Local Scientific and Organizing Committee

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ABSTRACTS

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KEYNOTE LECTURES

The Impact of War and Conflict on Women and Children (personal experiance)

Izzeldin Abuelaish[1]

[1]Global Health Division - Dalla Lana School of Public Health; University of Toronto, Torronto, Canada

War and conflict are dynamic and changing. The types and impact of wars which have emerged are beyond the battlefield. Its not the soldier who is killed or wounded, its the innocent child, daughter, mother, and elderly individual. It is our children and grandchildren who are dying before they are fully adults, or who live the rest of their lives with battle wounds, whether physically and/or psychologically, completely altering their life's trajectory.I experienced it through the killing of my three daughters, niece and wounding other family members when an Israeli tank shelled my house January 16, 2009.

The major prices of war and conflict are paid by women and children. During war and conflict, women and children are in a very vulnerable position. Women and children are impacted directly and indirectly, both short-term and long-term, through physical and (less visible) structural violence 2,3. During conflict, violence in many forms leave women and children more susceptible to displacement, long-term physical, behavioural, and mental health consequences, and ultimately death,2,3,4. In fact, over the last two decades (2000-2019), armed conflicts classified as wars were associated with an increase of 36.9 maternal deaths per 100,000 live births, and an increase of 2.8 infant (under 1 year old) deaths per 1,000 live births (Jawad et al., 2021)5. While violence against women and children is often used as a weapon of war, concomitantly, women and children are weaponised as a means to an end in the context of conflict 2,3. Lack of accountability by governments, and a lack of a holistic, and comprehensive global assessment of the impacts of conflict on maternal and children's health need to be addressed, to reduce the burden of disease and injustice and inequality faced by this vulnerable population. War is genocide, torture, propaganda, dishonesty, and slavery of humanity. War and injustice are not just to be documented but to be prevented.

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Relevance for users and families:

Not recived.

Foundation Paralysie Cérébrale Lecture: Achieving Lifelong Care and Support for Individuals with Cerebral Palsy

Emma Livingston
[1]UP – The Adult Cerebral Palsy Movement, London, United Kingdom

Cerebral palsy (CP) is the largest child onset physical disability. It is a lifelong condition, with over two-thirds of its population being adults. This conference presentation will discuss the current knowledge about CP, including life expectancy, degenerative impacts, and comorbidities. I will emphasise the need for a lifelong perspective on care, which is currently lacking, and the consequences of this deficiency, such as poor care and low participation in work and social activities.

Drawing on personal experiences, I will explore the key elements of effective lifelong care and support for individuals with CP. This includes fostering ambition and participation, promoting self-care and healthy habits, and ensuring coordination between medical and social services. I will also discuss the importance of accessible information and support for individuals with CP and their families.

Moreover, I will delve into the interventions by institutions in the United Kingdom like NICE and the All-Party Parliamentary Group (APPG) on CP, in improving care transitions and defining what good care looks like for people with CP. By comparing CP care to that for other conditions like stroke and multiple sclerosis, I will highlight the need for proactive interventions in CP management.

Furthermore, I will examine the cost benefits of providing lifelong support for individuals with CP and the roles played by medical, social, and third sectors in facilitating this care. Lastly, I will present examples of knowledge translation and emphasise the importance of personal empowerment in fostering better outcomes for those living with cerebral palsy.

Relevance for users and families:

This presentation focuses on the importance of a lifelong care approach for individuals with cerebral palsy (CP). By exploring key elements of effective support, such as fostering ambition, self-care, and coordination between medical and social services, we aim to empower families and individuals in advocating for improved CP care. We will discuss the role of accessible information, institutions, and personal empowerment in enhancing care outcomes and the quality of life for those living with CP.

Elsass Foundation Lecture: Reconsidering our paradigms: Lessons for better futures from intervention studies

Helene Polatajko[1]

[1]Department of Occupational Science and Occupational Therapy, Rehabilitation Sciences Institute, University of Toronto, Neuroscience Program, Toronto, Canada

It is generally agreed that health, well-being and participaiton arekey goals for all, including those with differing abilities.It is no longer acceptable to simply address the health needs of children with disabiities, children and their families tell us it is imperative that we also address their needs for well-being and participation.The latter requires a rethinking of our appraoches to children with disabilities and their families.It is now quite clear that interventions focused on impairment reduction and health management do not adequatey meet these needs – it is quite clear that impariment reduction does not equate with participation. Rather, a concerted, clinet-cnetredeffort is required to promote the acquisition of a skill repetoire that enables well-being and participation.Experince with a client-centredintervention approach focused on skill acquisution provides compelling evidence that impairment reduction is neither a sufficient condition,nor perhaps even a necessary condiiton,to support the acquistion of skills that are fundamental to well-being and participation.In this presentation, learnings from a series of skill-focused intervention studies will be used to argue for a paradigm shift in our approach to children and their families and to elucidate the key components of an enabling paradigm that supports well-being and participation.

Relevance for users and families:

This presentation is intended to bring into focus the importance ot addressing the well-being and participation of the children we serve and their families and the implications this has for the intervention approaches that have typically used in the addressing the needs of children with disabilities.Accordingly, this presentation is of great relevance to practitioners and families alike.

Best practices for the clinical management of chronic pain in children and adolescents

Minna Ståhl[1]

[1]Finnish Center for Pediatric and Adolescent Pain Management and Research, HUS New Children's Hospital, Helsinki, Finland

Prevalence of non-specific chronic pain has increased in western pediatric populations over the last three decades. In some, chronic pain is associated with functional impairment such as inability to attend school. More and more such patients with families are seeking help from pediatric hospitals. Multidisciplinary approach in treatment and rehabilitation would be needed. However, multiprofessional teams specialized into pediatric pain management and working interdisciplinary way are still scarce. Such unmet need was discovered some years ago in pediatric hospitals in Finland. For this reason, a national pediatric pain center was recently established with 2.7 million euros donation money. This session will present best practices for the clinical management of chronic pain in children and adolescents by making synthesis of the current scientific evidence and guidelines coupled with clinical experience and example.

Relevance for users and families:

Not recived.

Management of spine deformities in patients with low-tone neuromuscular diseases

Muharem Yazici[1]

[1]Children's Orthopaedics and Spine Center, Ankara, Türkiye

In general, neurological patients are more likely than healthy population to experience spinal deformity. Low-tone neuromuscular diseases are frequently accompanied by 3-dimensional collapsing spine deformities, including the pelvis. With diseases like SMA or DMD, this incidence is very close to 100%. Although the age at which the deformity becomes evident varies according to the diseases, the majority of them are progressive and the progression may continue after the bone development is completed. The development of deformity causes serious functional problems rather than aesthetics, impairing the quality of life of patients and affecting patient and caregiver satisfaction.

Sitting difficulties, pressure sores, gastrointestinal and pulmonary problems and pain are among the problems caused by advanced deformities. Especially respiratory and, as a consequence of this, heart-related problems have a shortening effect on life expectancy. Conservative treatment is both difficult to implement and has limited effectiveness. Surgical treatment is usually the only option for progressive deformities. Although spinal surgery generally carries risks, a successful surgery improves patients' quality of life and lengthens survival by avoiding deformity-related consequences. While growth-friendly Methods are preferred in growing children, definitive instrumentation and fusion are preferred in children aged 10 and over, whose lung development is largely completed.

Relevance for users and families:

The family of individuals who have low-tone neuromuscular conditions should be aware from the time of diagnosis that there is a high chance they will experience spinal deformity at some point in their lives, and diligent monitoring should be done in this regard. For managing progressive deformities, early surgical intervention lowers the risks and increases the likelihood of a successful outcome. These interventions can now be used successfully because to modern surgical and anesthetic Methods.

ORAL COMMUNICATION

Oral Communication: Early Diagnosiss

Interrater reproducibility of General Movement Assessment and Motor Optimality Scores in a large population-based cohort

Caroline Alexander[1,2], Natasha Amery[3], Alison Salt[2,3], Catherine Morgan[4], Alicia Spittle[5], Catherine Elliott[1,2], Jane Valentine[2,3]

[1]Curtin University, Perth, Australia, [2]Telethon Kids Institute, Perth, Australia, [3]Child and Adolescent Health Service, Perth, Australia, [4]Cerebral Palsy Alliance Research Institute, The University of Sydney, Sydney, Australia, [5]University of Melbourne, Melbourne, Australia

Introduction: Prechtl's General Movement Assessment (GMA) and the Motor Optimality Score (MOS) is used to assess infants motor repertoire at 3-5months. Early Moves is a population-based prospective cohort study of the predictive utility of GMA for developmental outcomes. The aim of this sub-study is to establish the inter-rater reproducibility of GMA, total MOS and MOS sub-scores within the Early Moves study.

Method: General Movement Assessment, including MOS, was assessed using 3-minute videos on 754 infants from the Early Moves cohort (mean gestation 38.8weeks [27.9-41.7weeks], mean birthweight 3334g [1580-4595g], 54% male). Videos were collected between 12+0 and 16+6 weeks post-term. All videos were independently scored by two assessors, randomly selected from a pool of six advanced trained assessors. Interrater reproducibility was assessed using percentage agreement and Gwet's Agreement Coefficient (AC) statistic for categorical variables, and intraclass correlation coefficient and Bland Altman analysis for continuous variables.

Results: Excellent interrater reproducibility was found for the gestalt assessment with 99.6%, and AC=0.996 (se=0.004). For the total MOS, ICC=0.922 [95%CI 0.910-9.932]. Bland-Altman analysis showed mean difference of 0.07, with limits of agreement of -2.44-2.58. Sub-score interrater reproducibility was very high with >80% agreement, and AC >0.76.Observed movement patterns had the highest reproducibility with 98.7% agreement and AC=0.986 (se=0.005). Though the lowest out of all sub-scores, reproducibility of the Movement Character was still very high with 81.7% agreement and AC=0.758 (se=0.019).

Conclusion: Excellent gestalt agreement and ICC values for total MOS, along with satisfactory interrater AC values were found in the large population-based study.

Relevance for users and families:

The general movement assessment and motor optimality score conducted at 3-5 months of age is scored very consistently between independent assessors.

Knowledge translation of early identification of cerebral palsy (KiTE CP) study: engagement in screening implementation among a high-risk prospective cohort of Australian infants

Amanda Kwong[1,2,3], Abbey Eeles[1,2,3,4], Catherine Morgan[5,6], Roslyn Boyd[7], Alicia Spittle[1,2,3]

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Introduction: International guidelines for detecting cerebral palsy (CP) early involves combining the General Movements Assessment (GMA), neuroimaging and physical assessment among high-risk infant populations by 5 months' corrected age. The current study aims to describe the implementation rate of infants who were screened for CP using a multi-modal knowledge translation approach in Australian healthcare settings that care for infants at risk of CP.

Patients and Methods: Infants were born <37 weeks' gestation who were considered high risk of adverse outcome based on prematurity or born at term with neonatal encephalopathy/complex medical history. Infants were cared for at one of 11 sites across the Australian states of Victoria, New South Wales and Queensland. Multi-modal knowledge translation included barrier identification, professional development and special-interest groups. Families were offered early CP screening by recording general movements using the Baby Moves app or clinically.

Results: 1460 infants were eligible for the study with 597 (41%) participating (44% female, 76% born preterm, 24% term). Of these 92% (548/597) infants were assessed using the GMA (64% Baby Moves app; 9% clinical video; 18% other method; 8% no video). Of these 548 infants, 23% (n=124) were assessed as having absent, 2% (n=10) abnormal fidgety movements; 74% (n=403) had normal fidgety movements, and 2% (n=11) were unscorable.

Conclusion: Early CP screening was adopted and implemented across participating sites using a multi-modal knowledge translation strategy. Recruitment rates were impacted by the COVID-19 pandemic. Contextualisation of the reasons for engagement in early screening from parents and clinicians-alike warrants further investigation.

Relevance for users and families:

This work details how early detection for cerebral palsy (CP) has been implemented across multiple sites in Australia. Screening for CP involved families as active participants of the screening process by using the Baby Moves smartphone app to record videos of their infant's movements. The Results of early screening uptake by families will be the basis for future studies exploring the parent-experience of early CP screening.

BabyOSCAR score at 3 months of age predicts GMFCS score at age 2 in infants with spastic CP

Colleen Peyton[1], Vanessa Barbosa[2], Barbara Sargent[3], David Aaby[1], Theresa Sukal-Moulton[1], **Lynn Boswell**[4]

[1]Northwestern, Chicago, United States, [2]University of Illinois, Chicago, Chicago, United States, [3]University of Southern California, Los Angeles, United States, [4]Ann and Robert H Lurie Children's Hospital of Chicago, Chicago, United States

Introduction: Individuals with spastic CP have difficulties with independent joint control (IJC; i.e. ability to move one joint at a time), but no clinical tool exists to measure IJC in infancy. Our aim was to create and validate a systematic approach to measure IJC in infancy called, "baby Observational Selective Control AppRaisal" (babyOSCAR).

Patients and Methods: One minute video clips of 3-month-old infant spontaneous movement were used to score 75 infants with known outcome at age ≥2 years. 45 infants had spastic CP (16 unilateral: 8 right, 8 left; 29 bilateral) and 30 infants had typical development (TD). A score of 1 was given each time an instance of independent joint motion was observed in the upper extremities (UE) and lower extremities (LE). The total score could range from 0 to 32. An asymmetry score was calculated by subtracting the right UE/LE from the left UE/LE.

Results: All children with TD had a score >22. A score ≤ 22 was 98% sensitive for having spastic CP. A score <13 was 98% sensitive for having an outcome of GMFCS levels IV-V and a score ≥ 13 was 75% specific for GMFCS levels I-III. Infants with an absolute asymmetry score of ≥5 were significantly more likely to have unilateral CP ($p<0.001$) than children with TD or bilateral CP. BabyOSCAR score at 3 months was significantly associated with GMFCS level at ≥2 years of age.

Conclusion: BabyOSCAR is a valid and promising method to measure IJC in 3 month old infants.

Relevance for users and families:

The BabyOSCAR may help to 1) improve prognosis at an earlier age and 2) target treatments towards the joints of the body that have less observed selective control in infancy.

Reliability of the Motor Optimality Score-Revised: Studying infants at elevated likelihood for adverse neurological outcome

Maria Örtqvist[1], Peter Marschik[2,3,4], Moreno Toldo[5], Dajie Zhang[2,3], Viviana Fajardo[6], Karin Nielsen-Saines[6], Ulrika Ådén[1,7], Christa Einspieler[3]

[1]Karolinska Institutet, Department of Women's and Children's health, Stockholm, Sweden, [2]Department of Child and Adolescent Psychiatry and Psychotherapy, SEE – Systemic Ethology and Developmental Science, University Medical Center Goettingen and Leibniz ScienceCampus Primate Cognition, Goettingen, Germany, [3]iDN -interdisciplinary Developmental Neuroscience, Division of Phoniatrics, iDN, interdisciplinary Developmental Neuroscience, Medical University of Graz, Graz, Austria, [4]Center of Neurodevelopmental Disorders (KIND), Center for Psychiatry Research; Department of Women's and Children's Health, Karolinska Institutet & Child and Adolescent Psychiatry, Stockholm Health Care Services, Stockholm County Council, Stockholm, Sweden, [5]Department of Medical Rehabilitation, Kiran Society for Rehabilitation and Education of Children with Disabilities, Varanasi, India, [6]UCLA School of Medicine, Los Angeles, USA, [7]Linköping University, Sweden; Crown Princess Victoria's Children's and Youth Hospital, University Hospital, Linköping, Sweden

Introduction: The General Movement Motor Optimality Score-Revised (MOS-R) can be performed during 3-5 months corrected age to predict neurological impairments. The study aimwas to evaluate the reliability values of the MOS-R (subcategories and total score) when used in a large cohort of three independent groups of infants at elevated likelihood for adverse neurological outcome. An additional aim was to evaluate the reliability when assessing the infants at different age-spans.

Patients and Methods: MOS-R were assessed in three groups of infants by two assessors/cohort. Infants were recruited from projects in Sweden (infants born extremely preterm), India (infants born in low-resource communities) and the USA (infants prenatally exposed to SARS-CoV-2). Intraclass correlation coefficients (ICC) and kappa (κw) were applied. ICC of MOS-R subcategories and total scores were presented for cohorts together and separately as well as for age-spans: 9-12, 13-16, and 17-25-weeks post-term age.

Results: 252 infants were included (born extremely preterm n=97, born in low-resource communities n=97, prenatally SARS-CoV-2 exposed n=58). Reliability of the total MOS-R was almost perfect (ICC 0.98-0.99) for all cohorts, together and separately. Similar Results were found for the three age-spans (ICC 0.98-0.99). Substantial to perfect reliability was shown for the subcategories (κw; 0.67-1.00), with postural patterns showing the lowest value 0.67.

Conclusion: The MOS-R can be used in high-risk populations with substantial to perfect reliability, both in regards of total/subcategory scores as well as in different age groups. However, the subcategory postural patterns as well as the clinical applicability of the MOS-R needs further study.

Relevance for users and families:

Early identification of neurodevelopmental impairments in vulnerable infants remains challenging but is crucial for early interventions and improving outcomes. Even though analysis of the MOS-R requires an advanced scorer and is somewhat more time-consuming than categorical GMA, there is an advantage to carry out detailed assessment of an infant's motor repertoire. The MOS-R can give a more specific motor profile of the child and guide clinicians planning targeted treatment and early intervention.

Relationship between infant motor repertoire at 3-5 months and early neurodevelopment on the hammersmith infant neurological examination in a cohort of 'at risk' Aboriginal and Torres Strait Islander infants

Carly Luke[1], Arend Bos[2], Robert Ware[3], Anya Gordon[4], Chloe Taifalos[5], Hailey Williams[5], Katherine Benfer[1], Margot Bosanquet[4], Roslyn Boyd[1]

[1]Queensland Cerebral Palsy And Rehabilitation Research Centre (qcprrc), South Brisbane, Australia, [2]University of Groningen, University Medical Center Groningen, Beatrix Children's Hospital, Division of Neonatology, Groningen, The Netherlands, [3]Menzies Health Institute Queensland, Griffith University, Brisbane, Australia, [4]Townsville University Hospital (TUH), Townsville Hospital and Health Service District (THHS), Townsville, Australia, [5]Cairns Hospital (CH), Cairns and Hinterland Hospital and Health Service (CHHHS), Cairns, Australia

Introduction: Early screening of infants 'at risk' of later adverse neurodevelopmental outcomes (NDO) enables infants to be fast-tracked to targeted interventions.This study examines the relationship between infant motor repertoire using the General movements Optimality Score (MOS-R) and neurodevelopmental status at 4-9 months CA on the Hammersmith Infant Neurological Examination (HINE) to determine predictive validity.

Patients and Methods: A prospective cohort of 132 'at risk' infants were assessed on the MOS-R via videos of their spontaneous movements at 11-17 weeks CA.At 4 to 9 months CA age-specific cut-points on the HINE were used to classify infant neurodevelopmental status as i. on track, or 'at risk' of ii. cerebral palsy or iii. other adverse NDO.Regression modelling was used to determine the relationship between MOS-R and early neurodevelopmental status using the HINE.

Results: 92(70%) infants have completed both assessments, 46(50%) male, mean GA at birth 33.3 weeks. Of these 50(54.4%) were developing 'on track', 27(29.4%) 'at risk of NDO' and 15(16.3%) 'at risk of CP'.Optimality scores (mean=19.6, SD=5.9) were moderately correlated with HINE scores (mean=63.9, SD=11.3).Infants who were 'at high risk of CP' had significantly lower MOS-R scores (mean=12.0, SD=6.8) than infants at risk of other NDO (mean=20.9, SD=3.8) or those developing 'on track' (mean=21.1, SD=4.9).

Conclusion: The MOS-R is positively related to HINE scores at 4-9 months CA.Optimality scores equivalent to 'high risk of CP' were a strong predictor of HINE scores below an age-specific CP cut-point.

Relevance for users and families:

Babies who are born early, low birth weight or who require extra support in hospital after birth, have a higher chance of developmental vulnerability and may require extra support to move, learn and play.Early screening programs can identify infants who are 'on track' with their development and those who require extra support.Using predictive tools enables earlier access to targeted support services, optimising brain development during the crucial period of growth.

Telemonitoring of motor skills using the Alberta Infant Motor Scale: feasibility and comparison with face-to-face assessment

Adriana Neves dos Santos[1], Rafaela Silveira Passamani[1], Carolina Kazumi Shigihara[1], Herika de Vargas Ciello[1], Luize Souto Ceolin[1]

[1]Federal University Of Santa Catarina, Araranguá, Brazil

Introduction:Telemonitoring motor skills might be an alternative for the early detection of motor impairments. We aimed to verify the feasibility of remote motor assessment and compare it with face-to-face assessment.

Patients and Methods:Approved by the local Ethics Committee (UFSC-CAAE: 54379221.5.0000.0121). We applied the Alberta Infant Motor Scale (AIMS) with 48 infants twice, randomly: a) remotely (synchronous video calls), b) face-to-face. We compared assessments using the Wilcoxon test. We verified feasibility of remote assessment with a questionnaire.

Results: No difference between assessments for supine (Z=-1.90; p=0.06), prone (Z=-1.39; p=0.16), sitting (Z =-0.71; p=0.48), and standing (Z=-1.15; p=0.25) scores of the AIMS. There was a difference in the AIMS total score (Z=-2.18; p=0.03) between remote (median=54.0) and face-to-face (median=53.5) assessments. Thirty-eight caregivers answered the questionnaire as follows: no technical issues (24) or difficulty using the remote device (34), facility to stimulate movements and understand the instructions (37), motor behavior as usually performed by the infant at home (35), excellent (25) and good (10) quality of the remote assessment, and similarity with face-to-face assessment (25). Fifty-five caregivers reported the following negative aspects of remote assessment: distraction of the infant with the camera (3), distraction with the noises at home (3), the infant was not in a good mood (8), and other people at home disturbed the assessment (1). Thirty-three caregivers would recommend remote assessment.

Conclusion:assessments conducted remotely by the mothers showed high feasibility. The remote assessment might be favored by the child's home environment, resulting in higher scores of the AIMS.

Relevance for users and families:

Remote assessment creates opportunities for the health professional to monitor child development at home. In addition, the remote assessment might allow infants with restricted access to specialized health services, including financially vulnerable people, to be assessed using standardized motor scales. Therefore, telemonitoring of motor skills has potential to allow the infant to be monitored in a family setting and increase equal access to health services.

Oral Communication: Epidemiology

SCPE Survey: Where Europe stands in the care of Cerebral Palsy (CP). Needs and inequalities

Antigone Papavasileiou[1], Agnieszka Kinsner-Ovaskainen[2], Sandra Julsen Hollung[3], Daniel Virella[4], Katalin Hollódy[5], David Neubauer[6], Malika Delobel[7], Anja Troha[6], Catherine Arnaud[7]

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Introduction: Health care disparities in the prevalence and severity of CP are known to be related to socioeconomic and minority status, maternal education and gender.

This survey aimed to record needs and barriers to health care in European children with CP.

Methods: A 27-item survey addressing availability and financing of health services was completed by 61 European clinicians and researchers, experts in CP and childhood disability, from 29 countries, between 29 April and 22 July 2022.

Results: In 70% of the responses availability of both public and private health care services was reported; in the rest, services were reported to be provided only via a public health system. Long waiting lists for public health providers were reported by 61% of the responders. No insurance coverage for parts of the population was recorded in 38% of the responses. Availability of specialised physicians for diagnosis and management of CP was reported by most, with Child Neurologists and Paediatric Orthopedic Surgeons prevailing in 93% of the responses. Availability of P/T, O/T, Speech and Language therapists trained in CP was reported by 90%; services for early diagnosis and early intervention in CP, by 80%. Variability of health care services was recorded within the same country, depending on location.

Conclusion: Availability and accessibility to health care for people with CP is not uniform among European countries and varies within the same country.

Moreover, public health services and insurance coverage for people with CP have to be improved in several areas.

Relevance for users and families:

Exploring health care needs and inequalities in the care of children with CP is important for implementing early and effective preventative and intervention policies even in high and middle-income countries.

Developing a Common Dataset for Children with Severe Neurological Impairment – A Scoping Review of Relevant Variables

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Introduction: Children with Severe Neurological Impairment (SNI) comprise a small but significant heterogeneous cohort with overlapping clinical characteristics, comorbidities and healthcare needs. The absence of data on this group is a barrier to meaningful planning for resource allocation for health and social care into adulthood and impedes progress in research to inform and manage morbidity and identify risk to longevity. This study aimed to perform a scoping review of the literature on clinical and research variables, data elements and core outcomes relevant to children with SNI and produce an initial dataset.

Methods: An international steering committee was formed and the project was registered with the Core Outcome Measures for Effectiveness Trials COMET initiative (www.comet-initiative.org/Studies/Details/ 1976). The scoping review was registered on Open Science Framework and utilised the PRISMA extension for scoping reviews as a guide. Searches were conducted of PubMed, Embase, CINAHL Plus and Scopus until February 2022 to identify datasets, elements, registry variables and outcomes relevant to this population.

Results: Database searches revealed 1766 Results. Once duplicates were removed, 1462 were screened for eligibility. An additional 15 records were obtained from other sources. 55 full texts were reviewed. Relevant variables were extracted from 37 records and a total of 187 variables were included in the initial dataset.

Conclusions: This scoping review formed the initial dataset that was used in establishing international consensus on a common dataset for children with SNI. This will be central to future comparative and collaborative research.

Relevance for users and families:

This research looks at all the data points that studies relevant to children with severe neurological impairment used, which then formed the basis to a process to establish the important factors for all studies in this group to examine. This means that centres around the world working together can produce really helpful information.

Unavoided cerebral palsy at 5-years of age is more frequently severe in asphyxic neonates born at term surviving induced hypothermia

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Introduction:Induced hypothermia (IH) reduces the occurrence of death or cerebral palsy (CP) among term neonates with moderate-to-severe hypoxic-ischemic encephalopathy (HIE). Is the severity of CP among survivors of HIE after IH similar to their counterparts not submitted to IH?

Patients and Methods: The Portuguese Surveillance of Cerebral Palsy registers 5-year-old children with CP, born since 2001. A partner of Surveillance of Cerebral Palsy in Europe, both share methodology. We retrieved clinic, imagiologic (main MRI finding) and function scores data from children born in Portugal between 2007 and 2013, ≥36 weeks gestation, admitted to neonatal care; we excluded: TORCH infection, brain malformation, syndrome causing neurologic compromise, and postneonatal CP. On a post-hoc analysis, children with MRI classified as C3-MCA infarction, C4-Normal or C5-Miscellanea were excluded. We compared 5-year-old survivors of HIE whereas submitted or not to IH, using Chi-square or fisher-exact tests.

Results: Children submitted to IH more often had predominant grey matter lesion (87%vs.70.5%; p=0.055), especially basal ganglia lesions (72%vs.48%; p=0.041). Dyskinetic:spastic CP ratio was 48.5%:48.5% if submitted to IH vs. 31%:69% if not (p=0.040). Those submitted to IH had worse function scores (BFMF IV-V 71%vs.42%, p=0.020; GMFCS IV-V 71% vs. 42%, p=0.016; speech intelligibility Viking IV 73%vs 60%, p=0.031; IQ<50 70% vs. 48.5%, p=0.037) and tended to epilepsy (69%vs.51.5%; p=0.080).

Conclusion: Children with CP, born at term, with HIE, if having been on IH, seem to have higher odds for predominantly dyskinetic CP, basal ganglia lesion, their function scores being lower and more likely to suffer epilepsy.

Relevance for users and families:

These data provide novel, useful information to complement the already known data provided by clinical trials and effectiveness studies on the ability of IH to prevent death or CP after HIE, characterizing the clinical and functional severity of CP at age 5 years-old among survivors of HIE after

H, compared with counterparts with CP not submitted to IH. It may be used to inform on prognosis and for anticipating intervention needs.

The Best Start Trial: Does ultra-early parent-administered physiotherapy improve motor outcomes in infants at high risk of cerebral palsy or motor delay – a randomised controlled pilot trial?

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Introduction: It is unestablished whether commencing ultra-early parent-administered physiotherapy in Neonatal Intensive Care Unit (NICU) to infants identified at high risk of cerebral palsy (CP) or motor delay, improves motor outcomes.

Patients and Methods: Infants meeting criteria of high risk of CP or motor delay were enrolled in a single blind RCT of experimental care (from 34 weeks corrected age (CA)) versus usual care physiotherapy at a Sydney NICU. The primary outcome was the Alberta Infant Motor Scale (AIMS) total score at 16 weeks CA. Secondary outcomes measures were (i) Depression Anxiety and Stress Score (DASS-21) and Parents Perceptions Survey (at 16 weeks CA); and (ii) Bayley Scales of Infant Development version 4 (BSID4) and Neurological Examination (12 and 24 months CA).

Results: All 30 infants enrolled received the assigned intervention until 16 weeks CA. There were no between-group differences for the AIMS score at 16 weeks CA (- 0.2, 95%CI -2.4 to 2.0) or DASS-21 **Results**. However, both the parents' "perception of treatment effectiveness" (2.1, 95%CI 0.5 to 3.7) and "perception of change" (1.8, 95%CI 0.6 to 3.1) were significantly in favour of the experimental group, and the parents did not perceive that the intervention was burdensome. The 12 month Results are pending in December 2022.

Conclusion: While data showed no between group difference for the AIMS motor outcome it is unclear if this is a result of the measure's psychometric properties or the treatment itself. Parents perceived that the treatment was effective and their infants had benefitted.

Relevance for users and families:

This work has high relevance for families of infants admitted to NICU and who have been informed that their infant is at high risk of CP or motor delay. The Trial investigated whether ultra-early parent-administered physiotherapy commencing in NICU was able to harness neuroplastic repair during early infancy to improve infant motor outcomes. Our findings contribute to the scant evidence base in this field and are also relevant to neonatal/paediatric clinicians.Longer-term outcomes are pending.

Knee and ankle range of motion and spasticity from childhood to adulthood in 3,223 individuals with cerebral palsy

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Introduction: Reduced range of motion (ROM) and spasticity are common in individuals with cerebral palsy (CP) and may affect gait, function and mobility. The aim was to analyse how hamstring length, knee extension, ankle dorsiflexion and spasticity in hamstrings and gastrocnemius change from childhood to adulthood.

Patients and Methods: A longitudinal cohort study of 3,223 individuals with CP, born 1990 to 2018, in the Swedish CP follow-up program. Analyses were based on 5,665 legs followed on average 8.6 years (0-25 years). Linear regression with random effect was used to follow the development of ROM and spasticity over time in relation to GMFCS level I-V.

Results: Knee extension and hamstrings length decreased during the entire follow up period for all GMFCS levels but mostly for level IV-V. Ankle dorsiflexion decreased during the entire follow up but most rapidly until 6-7 years of age. Gastrocnemius spasticity increased to 5-6 years of age and then decreased, whereas hamstring spasticity peaked at 5-8 years of age and then remained stable or decreased slightly.

Conclusion: Knee extension, ankle dorsi flexion and hamstrings length decrease up to adulthood. Gastrocnemius spasticity decreaseafter 6 years of age while hamstrings spasticity remain stable or decrease slightly after the initial peak.

Relevance for users and families:

These Results can contribute to develop follow up and interventions for individuals with CP based on GMFCS level.

Cerebral blood flow and structural connectivity before and after cognitive or motor training in pediatric cancer survivors

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Pediatric cancer survivors (PCS) frequently experience long-term functional difficulties. Improving cognitive and motor performance (i.e., functional outcome) is therefore crucial in PCS. The literature suggests cognitive and motor training may improve functional outcome and can entail structural and functional changes in the brain. The aim of this study is to examine training-induced neuroplasticity in PCS in relation to functional outcome after cognitive or motor training when compared to a control group.

Twenty-nine children after non-central nervous system cancer (≥ one year since cancer treatment) were examined over three time points (prior to, immediately after eight-weeks of training and at a three-months follow up). Cognitive functions were assessed with neuropsychological tests and motor abilities using the German Motor Test. Besides investigating global cerebral blood flow (CBF; measured by arterial spin labeling), region of interest analyses were conducted using cortical regions of the working memory and motor networks. Further, structural connectivity (SC; measured by diffusion tensor imaging) was estimated using the q-space diffeomorphic reconstruction algorithm.

Preliminary Results revealed that CBF was significantly lower immediately after cognitive training compared to baseline ($z = -2.073$, $p = .038$). Further, SC was significantly higher at a three-months follow up after cognitive training compared to baseline ($z = -2.240$; $p = .025$). No changes in CBF and SC were found after motor training.

The findings of this study might extend our knowledge on training-induced neuroplasticity in relation to functional outcome in PCS. Learning more about the training-induced neuroplasticity is essential to advance the quality of aftercare.

Relevance for users and families:

Pediatric cancer and its treatment can cause long-term cognitive and motor difficulties.These long-term difficulties can further affect academic skills and quality of life in pediatric cancer survivors. Hence, training cognitive and motor functions and understanding underlying brain mechanisms of training effects is important.

Oral Communication: Oral Function

Dynamic Imaging Grade of Swallowing Toxicity (DIGEST) in Children: Criterion Validity Against The Pediatric Version of The Eating Assessment Tool-10

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Introduction: the Fiberoptic Endoscopic Evaluation of Swallowing (FEES) could be used as a gold standard method for swallowing evaluation in pediatric patients. There is a need to define FEES Results in a standardized way in pediatrics. The Dynamic Imaging Grade of Swallowing Toxicity Scale (DIGEST) was developed to evaluate pharyngeal swallowing performance in adult patients. This current study was aimed to adapt and validate DIGEST by comparing the Pediatric Version of the Eating Assessment Tool-10 (PEDI-EAT-10) in children.

Patients and Methods: A total of 30 children were included. FEES was performed to evaluate swallowing performance. The penetration and aspiration scale (PAS) was used to define penetration and aspiration severity, and DIGEST-FEES was used to evaluate safety (DIGESTs), efficiency (DIGESTe), and overall pharyngeal swallowing performance (DIGESTt). Dysphagia symptom severity was determined by the PEDI-EAT-10. Criterion validity against PEDI-EAT-10 and PAS was assessed with Spearman test, and the PEDI-EAT-10 scores between DIGEST grades were also compared.

Results: There were moderate to strong correlations between PEDI-EAT-10 and DIGESTs ($r=0.72$, $p<0.01$), DIGESTe ($r=0.52$, $p=0.003$), and DIGESTt ($r=0.68$, $p<0.01$). Moderate correlations were found between PAS and DIGESTs($r=0.45$, $p=0.01$) and DIGESTt ($r=0.43$, $p=0.01$). It was detected that there was difference between DIGEST grades in terms of PEDI-EAT-10 scores ($p=0.005$), of which the PEDI-EAT-10 score increased as the swallowing performance decreased according to DIGEST.

Conclusion: In Conclusion, DIGEST-FEES could be used as a valid scale to evaluate severity of pharyngeal dysphagia in pediatric patients. In future studies, other psychometric features should be assessed to support current Results.

Relevance for users and families:

Relevance for users and families: DIGEST-FEES will be helpful for clinicians to define safety, efficiency, and overall pharyngeal swallowing performance in pediatric patients, and could be used to specify dysphagia management plan.

Investigation of the relationship between oro-motor skills and gross motor abilities in children with dyskinetic cerebral palsy

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Introduction: The study aimed to investigate the relationship between oro-motor skills and gross motor abilities in children with dyskinetic cerebral palsy (CP).

Materials and Methods:Forty children with dyskinetic CP aged between 5-18 were. Presence and severity of dystonia and choreoathetosis overflow movements were assessed with the Dyskinesia Impairment Scale. The use of oro-motor skills, with EDACS; gross motor abilities was evaluated with GMFCS. This study received ethical approval (GO-22/536). Spearman's correlation test was used to evaluate the relationship among data.

Results: Of the children participating in the study, 17 were girls and 23 were boys, with a mean age of 12.88±4.57. A moderate correlation correlation (rs=0.58) between EDACS, and GMFCS were found in children with dyskinetic CP (p=0.001). There was also a high correlation (rs=0.72) between the EDACS, and GMFCS in children with choreoathetosis overflow movements (p=0.014). No correlation was found between the EDACS, and GMFCS in children with dystonia overflow movements.

Conclusions: As a result of this study, it was thought that as the ratio of gross motor abilities of children with Dyskinetic CP increased, their oro-motor skills were also better, so that more positive effects could be seen in their participation in social roles. The Results of the current study also that child's ability to control the tone, their stability, symmetry and degree of independence must be carefully assessed in children with feeding difficulties. It is important for Physiotherapists to consider their intervention programs, considering that oro-motor skills will be affected as the choreotetoid overflow movements increase

Relevance for users and families:

The work presented here is relevance parents to people with lived experience, their family members and others involved.

Motherese phonation style during interactions with pre-linguistic infants at high risk of Cerebral Palsy

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Introduction: Infant-directed speech (IDS), or motherese, typically differs from conversational adult speech in terms of style and content, and is crucial in the dyadic communication and coordination between a parent and a baby. While many IDS properties are universal, they also depend on both speaker and recipient factors. We investigated how high risk for neurological impairments may affect the quality of early vocal interactions infants participate in.

Patients and Methods: Spontaneous interactions between 4.5-month-old infants at high neurological risk and their mothers (N=14) were recorded and acoustically compared to those of typically developing (TP) infants (N=14) and their mothers.

Results: A significant difference was detected in the maternal voicing ratio, namely the proportion of voiced speech of all speech. Specifically, mothers of the high-risk infants used significantly less voiced speech compared to controls ($p<0.05$) and the amount of voicing systematically decreased with increasing severity of the infant long-term neurological outcome. A subgroup analysis of mothers' phonation styles revealed that breathy phonation was more common toward infants with severe long-term outcome, namely Cerebral Palsy (N=7; 44.7% of speech) compared to infants at risk with a mild or healthy long-term outcome (N=7; 16.5%) or TP infants (N=14; 22.0%). Finally, whispering was also more frequent in mothers of infants with a severe outcome (20.9%) compared to mothers of control infants (9.1%).

Conclusion: Overall, these Results indicate that systematic recipient-dependent differences in maternal phonation exist and depend on theinfant neurological condition. Importantly, such differences are already observable in speech directed at pre-linguistic infants.

Relevance for users and families:

Early parent-infant intersubjectivity has been shown to be challenged with infants at high risk for neurological impairments. These findings provide new insights about early vocal parent-infant interactive exchanges. This may inform new strategies of early intervention to support the parent-infant relationship in families with infants at high risk of neurological disorders, including Cerebral Palsy.

Scoping review of the Communication Function Classification System (CFCS)

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Introduction: The Communication Function Classification System (2011) classifies communication into 1 of 5 distinct levels based on sending/receiving messages with familiar/unfamiliar partners: The level is based on all communication Methods including aided and unaided augmentative and alternative communication (AAC). While originally used with cerebral palsy, the CFCS has since been used with other populations. Research Question: In the 10 years since the CFCS publication, how has the CFCS been used?

Methods: For this scoping review, a cited reference search for 'Hidecker, M*, 2011' was conducted.

Results: This method identified 366 articles citing the CFCS. Of the 366, 146 mentioned the CFCS in background information and 199 used the CFCS for research purposes. Of the articles that used the CFCS for research purposes, 172 used the CFCS level as a participant description but only 44 reported participants' AAC Methods of communication.

Conclusions: Since its 2011 publication, the CFCS has been translated into more than 25 languages. Many use the CFCS as part of a classification family including the GMFCS (1997), the MACS (2006), and the EDACS (2014). CFCS levels but not the AAC Methods are usually reported.

Relevance for users and families:

Research studies of individuals who use AAC need to report participants' AAC Methods. In cerebral palsy studies and likely in other disability studies, an underestimation of the number of patients that require AAC Methods is likely. If an individual with a communication disorder is not at a CFCS level I, AAC should be considered as an option.

Building a support system for persons with complex communication needs in Poland – a journey from a personal via local to national level.

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Objectives: The objective of the oral communication is to present how personal experience and determination combined with professional engagement and creativity may lead to building networks and introducing changes on local and national levels.

Target audience: Parents, speech, language and developmental therapists, occupational therapists, physiotherapists, multi-disciplinary teams ,physicians.

Summary: Each mum and each dad wants to hear these magic words from their children, „mum", „dad". Each parent wants their child to speak. But communication is not just about speaking, sometimes it is not about speaking at all.

Communication is one of the most important aspects of our life. We use communication to interact socially,to build relationships, to express personal preferences and feelings, to make comments and share opinions, make choices, ask for and give information (Communication Bill of Rights National Joint Committee for the Communication Needs of Persons with Severe Disabilities (NJC)). By interacting with others, children encounter and solve problems, communicate, and learn to consider others' perspectives.

In our presentation we would like to present how a parent's determination combined with professionals' engagement has led to implementing Augmentative and Alternative Communication services in a local school dedicated to children with complex communication needs, building networks and preparing suggestions for solutions and Augmentative and Alternative Communication services implementation on the national level.

Relevance for users and families:

The presentation is based on personal experience of one of the speakers as a mother of a person with complex communication needs. This personal path might be an inspiration for other parents on how to build partnership with professionals and networks to introduce change not only on personal but also local and national level.

Identifying feeding and swallowing disorders and malnutrition in children with neurological impairments

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Introduction: Feeding and swallowing disorders (FSD) and malnutrition are frequent in neurologically impaired children. There are several screening tools designed for both professionals and parents. We aimed to assess the usefulness of screening tools designed primarily for neurotypical children in the population of children with neurological impairments.

Patients and Methods: 42 children (29 boys), in average 4,8 years old, with neurological impairments were included. All were assessed with the Slovenian translation of Screening Tool for the Assessment of Malnutrition in Paediatrics (STAMP) and Paediatric Eating Assessment Tool (PediEAT). Data about perinatal events and feeding history were reported by parents, including the present feeding routine. Children's weight and height were measured. Children at risk for malnutrition or FSD were assessed by a speech and language therapist (SLT) and a dietitian. If needed children received feeding therapy, nutritional counselling and/or medical nutrition therapy.

Results: 38 (90.5%) children were identified as being at risk for malnutrition, while 23 (54.8%) were identified as being at risk for FSD. 52.4% of children were identified as being at risk by both screening tools. Total scores of STAMP and PediEat were not in correlation (p=0,239) and no obvious correlation was found between both screening tools and clinically identified problems by a SLP and a dietitian.

Conclusion: The Results showed a need for a specific combined screening tool for both FSD and malnutrition adjusted for children with neurological impairments. The tools used in the study lack the sensibility and specificity for this population.

Relevance for users and families:

Relevance for users and families: FSD often lead to malnutrition and other medical problems. Developing an effective screening tool could contribute to an earlier identification of feeding and swallowing disorders and malnutrition in all institutions working with children with neurological impairments.

Oral Communication: Family and Wellbeing 1

Families with children and adolescents with cerebral palsy: concerns in everyday life

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Introduction: Cerebral palsy (CP) is the most common cause of motor disability in childhood and is accompanied by many comorbidities. We do not know which impairments and issues cause families of children with CP concern in everyday life; thus, we aim to uncover the most prominent sources of concern.

Patients and Methods: We invited families with 2- to 18-year-old children registered in the Swiss Cerebral Palsy Registry (n=612) to participate in a survey on topics of concern. We addressed 47 topics based on the health, functioning and wellbeing traffic light system. We assessed extent of concern by topic and level of attention these topics receive by treating physicians. Families received a questionnaire for parents, and one for adolescents (12-18 years), if applicable.

Results: Preliminary Results show that participants are representative in terms of physical limitation, region, and gender (353 replies by September). Parents' responses (n=274) indicate that 'development of physical limitation', 'manual ability', and 'independence' most often cause concern (>60%). About 40% of parents state that e.g., unpleasant feelings, leisure, sexuality, and receipt of information need more attention by physicians. Provisional Results indicate that topics of concern differ between parents and adolescents. Additional Results of parents and adolescents will be available in January.

Conclusion: Our study reveals which topics cause families of children with CP concern in everyday life. These topics must be further investigated to improve the families' care and quality of life. Also, we uncover areas needing more attention by physicians.

Relevance for users and families:

We uncovered areas causing families of children with CP concern and in which families need more support by treating physicians. Together with patient representatives we will develop recommendations on how to advance care and support of young patients with CP and their families

based on these findings. Also, we aim to analyze these topics in depth to further improve patients and family's quality of life by developing appropriate intervention strategies.

Qualitative perspective upon family wellbeing of Early Childhood Intervention beneficiaries in the Republic of Moldova

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The paper explains the concerns of ECI service in Moldova, analyses the quality family life of ECI beneficiaries in post Covid-19 crises, assesses the degree of stress and anxiety of the caregivers in crises as well as the integration of concepts as sustainability and resilience in the national ECI sector.

The research sample included 43 adults, parents of children with developmental disorders or disabilities, 36 mothers and 7 fathers, beneficiaries of ECI "Voinicel" Center services and 6 national specialists in ECI. Research tools used: Social survey, Family Quality of Life Questioner, Beck Anxiety Inventory and Focus Group interviews.

The research identified that 70% of ECI beneficiaries face complex financial problems, 28% of respondents report a medium financial well-being. Most stringent problems encountered by ECI beneficiaries are physical and mental overwork (30%), the inability to engage in work due to permanent assistance of the disabled child (30%), isolation (10%) and lack of communication (8%).

Only 51% of respondents perceive family climate as relatively stable, family interaction being relatively low: 64% of respondents attest a low level of interaction, 33% - average interaction and 3% notes a high level of family interaction.Additionally, 51.5% of respondents do not receive support related to child's disability. Emotional well-being of ECI beneficiaries is extremely affected. The fear of death and insecurity prevail.

Relevance for users and families:

The Covid-19 pandemic, counteracted with war crises has greatly affected FQL of ECI beneficiaries, limiting them from service provision and increasing the level of stress and anxiety. Urgent, actions in stress reduction and parental support are required, alongside complex, financial and social support focused on long term perspective. Although ECI is globally recognized and embedded in the 2030 SGD Agenda, the course of this field should be prioritized and implemented at national level.

A feasibility study on the effect of locomotor training and task specific practice on quality of life in pre-school aged children with neurodevelopmental disorders.

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Introduction: Quality of life is an important measure when developing new interventions for children with neurodevelopmental disorders (NDD). We aimed to determine the potential efficacy of a group based, pre-school aged locomotor training and task specific program on quality-of-life measures.

Patient and Method: Forty-two children with NDD (mean 3.4y, SD 1y; GMFCS levels (or equivalent) II to V) participated in a locomotor training program (3, 2-hour sessions/week over 4 weeks). Co-morbidities included epilepsy (n=29), vision impairment (n=9) and hearing impairment (n=5). Caregivers completed the Infant and Toddler Quality of Life (ITQOL) at the start of the program (TP1), at the end of the program (TP2) and at 4-weeks follow-up (TP3). Linear mixed models were used to compare within group differences.

Results: There were significantly reduced ($p<0.05$) scores for the domains of satisfaction with growth and development, temperament, getting along with others, parental impact emotional scale and overall health at TP2 vs TP1. The effects were not consistently sustained in these domains at TP3 vs TP1.

Conclusion: The improvement in scores suggest that group-based intensive interventions can address important needs for the child and their family. The inconsistent carry-over of improved scores suggests changes in dosage are required and that further support for parents and their families is needed.

Relevance for users and families:

Relevance for Users and Families: Group based intensive programs have the potential to address important domains that affect quality of life. Further studies are required to determine ideal dosages for longer term benefit.

Investigating The Relationship Process of Care and Quality of Life in Cerebral Palsy: Parental Perspective

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Introduction: To investigate how process of care in (re)habilitation services are interpreted by parents of children with cerebral palsy and evaluate the relationship between process of care and health related quality of life (HRQL) of children.

Patients and Methods: 338 parents have children with cerebral palsy aged between 5-17 years, were included in this study. Children's parents completed questionnaires regarding perceptions of their children's HRQL (Child Health Questionnaire Parental Form: CHQ-PF-50) and their experiences of process of care in rehabilitation services (Measurement of Rehabilitation Processes: MPOC-20). Spearman's correlation coefficient was used for evaluating the relationship between CHQ-PF-50 and MPOC-20 subscales. Multivariate simple linear regression model was used to explain relations between CHQ-PF-50 and MPOC-20 subscales.

Results: Spearman's correlation analysis Results for the five subdimensions of MPOC-20 and the subdimension of CHQ-PF-50 correlation rank was between r=0.11-0.40 ($p<0.05$) and showed that the strongest correlation (r=0.405) was between the 'Providing Specific Information About the Child' subdimension of MPOC-20 and the 'Physical Functioning' subdimension of CHQ-PF-50. As a result of regression model, 'Enabling and Partnership', 'Coordinated and Comprehensive Care', 'Respectful and Supportive Care' subscales of MPOC-20 were predictors of subscales of CHQ-PF-50($p<0.05$).

Conclusion: The parental view of process of care in rehabilitation services affects HRQL in particular dimensions in children with cerebral palsy.

Relevance for users and families:

The parental view of process of care in rehabilitation services affects health related quality of life in particular dimensions in children with cerebral palsy. Therefore it is important to understand this relationship for goal setting.

The impact of developmental coordination disorder (DCD): preliminary Results in Belgium

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Introduction: Developmental Coordination Disorder (DCD) is a chronic neurodevelopmental disorder affecting one to two children in each school classroom. Children with DCD experience early-onset difficulties in motor coordination which significantly interfere with daily living activities and participation. Nevertheless, DCD is among the least known childhood disorders and is too often unrecognized and trivialized. This study aims to map the impact of DCD on the child and its family.

Participants and Methods: A total of 451 parents of children with DCD have completed the online questionnaire thus far (17/08/2022 to 25/11/2022) inquiring five domains: diagnostic trajectories, education, socio-emotional development, activities and participation, and therapy and intervention.

Results: Preliminary Results indicate that DCD is more than just a motor disorder as parents report, among others, articulation difficulties (53%), reduced sleep quality (51%), and difficulties making friends (46%). Care providers including (family) doctors (7-25%) and school staff (44-69%) had never heard of DCD. As 24% of children had to repeat at least one year of school, the educational system is failing these children. Astoundingly, 49% of parents indicated that they decided to work less to be able to better support their child, highlighting the direct financial impact.

Conclusions: With this large national study we can pinpoint the hiatuses in the diagnostic trajectories, the current needs of the children and their environment, and the financial burden for society. Our preliminary data suggest that society does not know what DCD is and is therefore unable to provide an inclusive encouraging environment for these children.

Relevance for users and families:

These Results can lead to better recognition of the experienced difficulties by professionals in healthcare and education. It may facilitate earlier diagnosis as people will know there is a 'term' for their difficulties. Additionally, the Results can empower individuals with DCD and their families as they will realize that they are not the only ones out there, but in fact thousands of other people around the globe face similar difficulties.

Oral Communication: Family and Wellbeing 2

Impact of ENVISAGE-Families workshops on outcomes for caregivers of children with neurodisabilities

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Introduction: ENVISAGE (Enabling Visions and Growing Expectations) is a parent-researcher co-designed program for caregivers raising children with neurodevelopmental disability (NDD). ENVISAGE provides evidence-based information, resources and tools for caregivers. We explored the impact of ENVISAGE on parent-reported outcomes of family empowerment, parenting confidence, family functioning, caregiver wellbeing and caregiver's perceptions of the family centeredness of services.

Patients and Methods: Caregivers of a child with NDD (6 years or younger) were recruited across Australia and Canada. Caregivers participated in five weekly online workshops, co-facilitated by a caregiver with lived experience and a clinician-researcher. Measures were collected at three time points: baseline (T1), immediately after (T2), and 3 months post-ENVISAGE (T3). Data were analysed using generalised estimating equations. Qualitative data were also collected and is presented elsewhere (see O'Connor et al).

Results: Sixty-five parents (86% mothers) were recruited. Parents' self-reported feelings of empowerment, increased on all subscales and the total score, with higher mean scores at T2 and T3 compared to T1 (all $p \leq 0.001$). For parenting confidence, we found evidence of changes from T1 at T2 and T3 ($p \leq 0.001$), and higher self-reported family functioning at T2 and T3 compared to T1 ($p \leq 0.001$). There was evidence of increased wellbeing scores at T2 compared to T1 for physical health (all $p \leq 0.001$).

Conclusion: Parent-reported improvements across most measures. While changes were modest, they were maintained over time. Caregivers benefit from access to programs to support them early in their experience of raising a child with NDD.

Relevance for users and families:

In all Phases of ENVISAGE, we have partnered with people with lived experience, their families, service providers and communities. This work reports on findings of the impact of this co-designed program on other caregivers who have previously not been involved with ENVISAGE.This work is relevant to

people interested in co-design, family engagement in research and integrated knowledge translation. It is also relevant to caregivers raising children with disabilities, their families, and service providers.

Online Healthy Mothers Healthy Families workshops: Positive health and lifestyle impact for mothers of children with disabilities.

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Introduction: Healthy Mothers Healthy Families (HMHF) is a program that educates and empowers mothers of children with disabilities to improve health behaviours.

Objectives: Evaluate the effectiveness of 20 online-HMHF workshops, co-lead by a trained mother-facilitators. Compare health behaviour and mental health outcomes for mothers who receive online-HMHF compared to controls.

Patients and Methods: A non-randomised trial was implemented across the COVID-19 pandemic, 2020-2022. Participants (N=241) selecting online-HMHF (n=144) or no intervention (n=97). Online-HMHF consisted of 3, 2 hour online interactive group workshops with e-workbook and self-paced online learning package. Outcome measures: Health Promoting Activities Scale (HPAS) and Depressional anxiety stress scales (DASS).

Results: Mothers (n=76) completing the online-HMHF group over 6-weeks experienced significant improvements compared to controls (n=63). Depressive symptoms reduced only in the online-HMHF group, F (1,170) = 12.55, p <.001, partial 2 = .069. There was significant difference in depressive symptoms between groups over 6-weeks, F (1,170) = 8.59, p =.004, partial 2 = .048. Stress significantly decreased only in the online-HMHF group, F (1,170) = 21.53, p <.001, partial 2 = .112. There was a significant difference between groups over 6 weeks F (1,170) = 6.66, p =.011, partial 2 = .038. Health behaviours (HPAS) significantly increased in the online-HMHF group only, F (1,110) = 13.63, p <.001, partial 2 = .110.

Conclusion: Compared to no intervention, the online-HMHF group experienced improved mental health, more frequent health promoting behaviours and reduced stress. This group-based, mother-facilitator lead, online-intervention with e-workbook and self-paced online package was effective for mothers.

Relevance for users and families:

The project involves mothers of children with a disability implementing a health intervention for other mothers. Consumer led intervention. Family centred intervention: mothers health matters. Downstream benefits for a child with disability includes better care and all family members benefit when mothers become empowered to prioritise their own health.

Scaling home programs for practicality and to help families recognise small steps of progress

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Home programmes are an integral part of the therapy to involve family members who can carry out therapeutic activities in different settings. The home programmes are designed to help the clients achieve incremental progress towards their short-term goal and to prevent the progression of secondary impairments such as tightness into contractures. Families do not always recognise small steps of progress in the clients. To help the clients and family members recognise small progressive steps, each therapeutic activity in the home programme can be scaled. We currently use the Canadian Occupational Performance Measure (COPM) to help our clients and their family members prioritise their concerns. The prioritised concerns are converted into smart, functional goals with the help of the therapist. The goals are scaled using the Goal Attainment Scale (GAS) to measure small progressive steps. We recommend three activities to our clients attending between October 2022 and March 2023 clients including babies, children, adolescents, and adults with cerebral palsy. Each activity is scaled using GAS for the client and/or the family members to check daily at home, for 21 days following the block of face-to-face therapy. The COPM and GAS are administered at the end of the initial therapy block and after 21 days of home-based therapy. A questionnaire will also be sent to the families to check the practicality of the home programme how it helped them to understand their children and if they were able to recognise small steps of progress. After six months, all data will be analysed.

Relevance for users and families:

Scaling home programmes will motivate the client and the family members to be consistent in practising recommended activities, improve the quality of activities performed by the clients at home and help family members to be realistic in their expectations.

‘Training as play’ – a change in the approach to training for parents of children with Cerebral Palsy after participating in a family-centered early intervention program ‘Good Start’

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Introduction: The Elsass Foundation offers a 4-day family-centered early intervention program to families with children with cerebral palsy (CP), called ‘Good Start’. The program seeks to improve quality of life by increasing family empowerment and sense of competence. This presentation focuses on the integration of a playful approach to meet the intensive training-need these families are faced with.

Methods: Data collection was carried out between October 2021 and September 2022. Four independent ‘Good Start’ courses were followed, providing data from a total of 19 families (38 parents). Observational data, interviews with parents (right after and 6 months after) and professional staff (physiotherapists, occupational therapists, psychologists, and the program-manager) are included.

Results: For the majority of families, training sessions changes from a burden, being very time-consuming and rigid, to a more integrated part of everyday life with a focus on ‘training as play’ and an awareness of training being part of all activities the child is involved in throughout the day. Parents express more energy, viable strategies to handle challenging situations and hope for the future. Goal setting and more systematic follow-up by the foundation appears to be important for long-term changes within the families. However, some families experienced this as missing to some degree.

Conclusion: A family-centered early intervention program, focusing on changing the mindset of training towards a playful approach which can be embedded in the family’s everyday life, positively affects the feeling of empowerment and quality of life for families with children with CP.

Relevance for users and families:

Family-centered early intervention, focusing on playful training can change the mindset and approach to training for parents of children with Cerebral Palsy, thereby positively influence the empowerment and quality of life for families with children with Cerebral Palsy.

An Analysis of Family Clustering of Psychological Factors in Children with Neurodevelopmental Disorders

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Introduction: This study was done on children consulting developmental pediatrician for different neurodevelopmental complains. 50 children were chosen, from clinical population, who were diagnosed with ASD by using Autism Diagnostic Observation Schedule-2 and Autism Diagnostic Interview–Revised, ADHD by using Conners, GDD by using Bayleys-3/Griffiths/WISC.

Patients and Methods: The total sample of children with NDDs was n=50 out of which male=41, female=9 and Mean age=5 years 5 months. A detailed family history, comprising of past three generation, of both paternal and maternal family was collected from parents/informants of children using a semi-structured interview. Thereafter, data analysis was done.

Results: Findings indicate that 56% families have history of anxiety-like symptoms and 4% have clinical diagnosis of anxiety disorder, 26% families reported history of depression-like symptoms and 2% diagnosed with clinical depression, 44% families show traits of OCD with 2% having the diagnosis, 66%suffer from emotional lability, 72% have history of anger outbursts, short temperedness and mood swings, 6% reported diagnosis of schizophrenia and 6% reported traits of hallucination and delusions. Suicidal ideation, suicidal tendency and suicidal deaths were found in 8%, 14% and 26% of the families respectively.

Conclusion: It may be concluded that high loading of psychological disorders or symptoms is found in families of children with NDDs. There is significant percentage of families with history of diagnosed psychopathology and greater percentage having symptoms that can further develop into a clinical disorder. Results indicate that psychological disorders in family history may be a predisposing factor in case of NDDs.

Relevance for users and families:

Families with high psychological load ought to be screened for NDDs and children presenting features of NDDs need thorough family history work-up for treatment planning as followed by Kolkata Development Model. (Bhattacharya A. 2019. EC Paediatrics 8.9)

Exploring the application, impacts and perceived value of the 'F-Words for Child Development' with multiple stakeholders in a special educational setting in Ireland.

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Introduction: Children's healthcare services in Ireland are undergoing radical change. It is an opportune time to integrate international best practice. In 2012, Rosenbaum and Gorter proposed a new philosophy to service delivery in the field of childhood disability called the 'The F-Words in Childhood Disability'. This evolving framework encourages clinicians and families to consider the 'F-Words' when exploring therapy goals with the child. Little attention has been given to the value of these 'F-words' in educational settings. This study aims to obtain multiple stakeholders' opinions in relation to the application and perceived value of the 'F-Words' within a special school setting in Ireland.

Patients and Methods: A mixed Methods research design was employed. Following ethical approval, the 'F-Words' were explored in six weekly sessions with stakeholders in a special school. Stakeholders included parents of children with disabilities, teaching staff, and youth with disabilities. Focus groups and standardised tests were administered before and after sessions.

Results: Preliminary Results suggest the 'F-Words' concepts were valued within the school setting. Sessions have led to teachers and parents committing to explore the use of these 'F-Words' in formulating Individual Educational Plans for individual students.Parent champions have emerged to co-design future F-Word sessions for special schools.

Conclusion: This study is one of the first of its kind to explore the F-Words within a special school. Further research is required to explore the potential of the F-words framework to support a more family centred, goal setting process when formulating Individual Educational Plans in these schools.

Relevance for users and families:

In times of change and a resource poor climate, a meaningful family centred approach can be lost from children's health and educational services. The 'F-Words for Child Development' may help support all stakeholders in special education to maintain a holistic view of the child and family, while continuing to support the students to achieve their educational potential.

Oral Communication: Transition into Adulthood

Preferences of children and adults with cerebral palsy on physical therapy towards the development of clinical practice guidelines: ESPaCe, a national survey in France

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Introduction: Integrating public-and-patient's perspective is a key step in guideline development. This study aimed at assessing people with cerebral palsy (CP) preferences regarding needs, barriers and expectations about physical therapy (PT), as part of the ESPaCe survey (Enquête Satisfaction Paralysie Cérébrale).

Patients and Methods: Needs, barriers and expectations regarding PT services were previously identified in a focus group study and included in a web-based/postal questionnaire. Participants self-reported or answered with the support of a family member. Preferences rated as 4/5 on a 0-5 Likert-scale were considered as strongly perceived. Analyses included multivariate adjustments on age, sex, GMFCS level, CP subtype, associated impairments, pain frequency, mother education and PT service provider.

Results: Out of 1010 participants in ESPaCe survey, 34% were children over age two, 16% were adolescents and 50% adults; 53% were GMFCS level I-III, and 47% level IV-V.A need for communication between professionals and for coordination were strongly perceived by 62% and 57% of responders, respectively. The barriers most frequently rated as important related to finding a physiotherapist "available" (41%) and "trained in CP" (53%), and "integrating PT sessions in my schedule" (36%). The expectations most frequently perceived as high were related to "physiotherapists' training in CP" (80%) and "patient's information regarding recommended Methods and exercises" (75%).

Conclusion: The ESPaCe survey confirmed the preferences more strongly perceived by participants: coordination and flexibility of care, access to therapists and receiving better information on recommended care. These main themes were later translated into national practice guidelines.

Relevance for users and families:

This survey is the voice of users and families. The assessment of preferences is particularly relevant for gathering evidence on the users and families' perspective on healthcare delivery. This survey confirms and prioritises the information previously collected in interviews and group discussions. It is key to highlight the topics that matter most to people with cerebral palsy and their families, such as coordination of care, which otherwise might be missed when developing national practice guidelines.

The Greenhouse for Autonomy and Independence: An Inclusive Project with Adults with Severe Cerebral Palsy to Prepare for the Transition from Assisted to Independent Living.

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Introduction: Adults with cerebral palsy report physical and emotional challenges in the transition from assisted to independent living. Although the literature describes difficulties, we found no intervention protocol for this move. The greenhouse for autonomy and independence was planned together with residents in assistive living to meet this need.

Patients and Methods: After receiving ethics approval, seven adults with severe cerebral palsy took part in interviews covering their expectations about living independently, fears and personal strengths as well as skills they wanted to learn. Interviews were audio-recorded, transcribed verbatim and coded by two researchers. The themes were drawn and presented to the participants for approval and alteration.

Results:Themes chosen were: Household management (sub-themes: finances, meals and maintenance), Interactions (with caregiver, family, friends and partners), Schedule (work, education and leisure) and My way (autonomy and independence, health management, emotions, self-advocacy and group power).An intervention protocol was developed from these themes consisting of weekly group meetings with a social worker and occupational therapist. Guest speakers included other professionals as well as peers who live independently. Participants also attended individual sessions to work on personal goals according to the Pathways and Resources for Engagement and Participation.

Conclusion: Inclusive research empower the participants and enable building interventions that meet the participants needs. The efficacy of the intervention is being studied. A multidisciplinary intervention created with the clients can provide a holistic solution to help adults with severe cerebral palsy in the challenge of moving from assisted to independent living.

Relevance for users and families:

Peole with severe cerebral palsy can participate in creating a program to help learn skills needed for independent living

Understanding the effectiveness of “Transition to Adulthood” interventions for adolescents with disabilities: A realist-informed mixed-Methods systematic review.

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Introduction: Youths with disabilities represent lower rates in post-secondary education and the workforce. Some "Transition to adulthood" programs have yielded positive outcomes; however, studies have yet to unpack the elements that contribute to the success of these programs. This review further explicated the contextual factors that activate the hidden mechanisms to enhance community integration for youth with disabilities.

Patients and Methods: We searched eight databases using PRISMA and RAMESES guidelines. Empirical studies adopted any methodology to study transition interventions for youth with disabilities were included. Thematic synthesis was conducted to identify patterns and generate context–mechanism–outcome configurations (CMOs).

Results: Forty-one studies met the inclusion criteria and covered various types of disability, and methodology of which intellectual disabilities and quantitative methodology constituted the highest percentage with 72% and 68%, respectively. The most common outcomes were gaining vocational skills to secure a job and preparing for post-secondary education. Many studies are underpinned theoretically at the individual or organizational level to reinforce self-determination or stakeholder partnership. Interventions with repetitive real-life practice offered peer interactions and engagement (C) and nurtured the sense of advocacy, confidence, and self-determination of these youths (M) to improve their knowledge and skills (O).

Conclusion: Our findings highlight the importance of developing transition programs that empower youths' self-advocacy, confidence, and ability to achieve and engage in the community through the supported repetitive real-life practice of needed skills.

Relevance for users and families:

Relevance for users and families: The findings highlight the importance of empowering youths with disabilities and their families to be involved early in the transition program development and map their needs to the services offered. Student-focused programs can lead to a seamless transition to adulthood. Also, parents, as essential stakeholders, should reinforce their children's peer relationships and independence.

Exploring young adulthood: Experiences and perceptions of participation for adolescents and young adults with cerebral palsy

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Introduction: The transition towards and through young adulthood involves significant self-discovery, changes in roles and expectations, and navigating relationships old and new. This qualitative study aimed to explore the experiences and perceptions of adolescents and young adults with cerebral palsy (CP) as they participate in daily life across major areas of adulthood. A secondary aim was to explore the impact of a newly established national, government-funded, disability insurance scheme on participation and health service access.

Methods: Semi-structured virtual and email-based interviews were conducted with 16 young adults with CP (16 –30 years, GMFCS I–V). Interviews were audio-recorded and transcribed verbatim, analysed by two researchers independently using reflexive thematic analysis.

Results: An overarching theme of 'branching out into adulthood' was identified. Participants described early adulthood as a time of change, choice, and challenge. Four main themes under this were identified: the desire to participate in adult life alongside peers; developing self-identity, especially of disability; the centrality of relationships and support networks; and building hopes for the future. Participants reported complex views on the new disability insurance scheme. While there was an 'unlocking of opportunities' through access to services and support, participants felt significant difficulty negotiating appropriate funding, resulting in frustration and reduced confidence in the scheme.

Conclusions: Young people with CP face complexity as they explore and participate in early adulthood. Health care providers and support networks need: greater expertise in adult CP, to discuss individual needs with honest conversations, and to provide appropriate and timely support, to maximise participation.

Relevance for users and families:

The findings of this study describe how adolescents and young adults with CP may like to participate in adulthood, the elements of life that are of most importance, and the relationships and structures that can support them to participate as they desire. The young people in this study offer ideas and strategies that may assist health funding bodies, parents, friends, and carers to understand how to best support them during this important transitional period.

A systematic review of social participation in adults with cerebral palsy.

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Introduction: Access to social participation opportunities for adults with cerebral palsy (CP) are in stark contrast to that of the general population. While CP is a non-progressive condition, the experience of living with CP changes as the individual grows up and additional difficulties in fully participating in society are faced due to pain, transportation needs and regular medical appointments. This review sought to identify and synthesise the current evidence on social participation in adults with cerebral palsy.

Methods: Four databases (PubMed, CINAHL Plus, PsycINFO and Web of Science) were systematically searched following pre-agreed eligibility criteria, and 15 articles were included in the review. A standardized data extraction tool was utilised alongside the Mixed Methods Appraisal Tool for quality appraisal.

Results: Papers included were qualitative, quantitative and mixed method, and ranged from 7 to 335 participants. The included studies were rated as high (n=10) and medium quality (n=5). Three themes emerged relating to how social participation in adulthood is impacted by age, mobility and environment. The review also highlighted the difficulties involved in defining social participation.

Conclusion: Inaccessible environments, a lack of appropriate support and increased difficulty with age were key factors in the limited social participation of adults with CP. Levels of social participation may be improved by considering timely interventions, enhancing independence and autonomy from a young age, and promoting physical fitness in childhood.

Relevance for users and families:

By providing information on what to expect when aging with CP, individuals may be better prepared for future physical challenges and experience improved social participation.

Social participation in adulthood may be enhanced by improving independence and autonomy in childhood and adolescence.

A supportive environment while growing up could improve social participation in adulthood as family support and expectations have been shown to impact the social participation of adults with CP.

Identifying and prioritising strategies to optimise community gym participation for young adults with cerebral palsy: an e-Delphi study

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Introduction:Community gyms are a preferred, safe and feasible space to be exercising for young adults with cerebral palsy, yet participation rates remain low. This study aimed to identify and prioritise strategies to optimise physical activity participation in the community gym setting for young adults with cerebral palsy.

Patients and Methods: With two consumer research partners, an e-Delphi method was conducted over three rounds with four stakeholder groups (young adults with cerebral palsy, their families, gym or exercise professionals, and health professionals). Strategies for change were identified by stakeholders in round 1. In rounds 2 and 3, strategies for change were rated on importance for implementation using a 7-point Likert scale (1 being lowest importance, 7 being highest). Consensus was achieved if ≥70% of participants identified a strategy as high importance.

Results: Seventy participants (20 young adults, 10 family members, 19 exercise professionals, 21 health professionals) identified 83 strategies for improving gym participation. Of these, 44 strategies met consensus for 'high importance'. The highest priority strategies related to changing the physical environment, addressing cost barriers, gym staff training, and developing partnerships between sectors.

Conclusion: Addressing physical accessibility of gym environments, cost of attendance, and gym staff skills and support were agreed by the stakeholder groups as priorities in future resource allocation and research translation. Social support in the gym was important to young adults but further research is needed to identify how to best operationalise its provision.

Relevance for users and families:

This study identifies priority implementation strategies perceived by relevant stakeholders to improve gym participation for young adults with cerebral palsy in community gym settings. The Results stem from the lived experiences of young adults, their families, and the leisure and health industries and interpreted in collaboration with two consumer research partners. Consumer involvement is critical to the identification of strategies relevant in local contexts, and in the design, implementation and evaluation of interventions.

Oral Communication: Advances in Management of Orphan Diseases 1

Reference curves of motor function outcomes in young steroid-naïve boys with Duchenne Muscular Dystrophy and healthy controls

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Introduction: Although gains in motor function are seen over the first years, young boys with Duchenne muscular dystrophy (DMD) do not achieve the same functioning level compared to healthy children. The aim of this study was to investigate functional motor performance in a large cohort of young steroid-naïve boys with DMD and age-matched healthy controls and to develop specific reference curves for both groups.

Materials and Methods: Cross-sectional data of 196 steroid-naïve boys with DMD aged 4 to 8 years and 497 healthy control boys aged 2 years 6 months to 8 years were included. Both groups were evaluated with the time to rise from floor test (TRF), 10-meter walk/run test, six-minute walk test (6MWT) and North Star Ambulatory Assessment (NSAA). Reference curves with percentiles 5%, 10%, 25%, 50%, 75%, 90% and 95% were estimated using quantile regression.

Results: Boys with DMD scored significantly lower in all functional motor outcomes compared to age-matched healthy controls ($p<0.001$), 89% to 95% of the boys with DMD scored below the 5th centile of the healthy controls. Functional motor outcome reference curves clearly differed between boys with DMD and healthy controls.

Conclusions: This study was the first to establish steroid-naïve DMD specific reference curves for functional motor outcomes and demonstrated that young steroid-naïve boys with DMD score significantly lower on the TRF, 10m walk/run, 6MWT and NSAA compared to age-matched healthy controls. The Results of this study might aid in the assessment and evaluation of treatment in young boys with DMD.

Relevance for users and families:

This study provides a detailed picture of functional motor outcomes in young steroid-naïve boys with Duchenne Muscular Dystrophy (DMD) compared to healthy controls. In addition, the reference curves for functional outcomes can support the assessment of a young boy with DMD in relation to the expected performance in aged-matched healthy controls as well as boys with DMD.

A preliminary ICF-CY Core-Set for the developmental management of infants with spinal muscular atrophy (Developmental SMA-CS).

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Introduction:Physiotherapy plays an essential role in early treatment of infants with spinal muscular atrophy (SMA). Disease-modifying drugs have changed the SMA-phenotypes significantly, enabling higher participation levels. Consequently, physiotherapists are now confronted with new challenges (Hjartarson,2022). The International Classification of Functioning, Disability and Health and its pediatric version (ICF, ICF-CY) enable feasible description and management of functioning and disability via ICF Core Sets (ICF-CS). ICF-CSs are short lists of the most relevant ICF-categories for a specific healthcare context allowing easy implementation, even in clinical setting, hence fostering clinical practice guidelines (Selb et al, 2015). No ICF-CS for the early intervention of infantile SMA is currently available. A preliminary SMA-specific ICF-CS for infants is presented.

Materials and Methods: Participation of infants with SMA was analysed by experienced neurodevelopmental physiotherapists, using videos taken during physiotherapy-sessions and daily situations. Developmental trajectories (typical communicative, exploratory, and motor behaviors), with their common environmental facilitators and barriers were identified. Equivalent ICF-categories were gathered to form a developmental ICF-CS, tailored to meet the unique needs of infants with SMA.

Results: A preliminary ICF-CS for infants with SMA was consolidated and then used in clinical practice as part of the on-going physiotherapeutic management of infants with SMA, thus enabling its further refinement.

Conclusions: Clinical experience and familiarity with the unique developmental trajectories of infants with SMA can lay the groundwork for an holistic SMA-specific ICF-CS, thus enabling the necessary paradigm-shift toward a higher standard of care. Further standard international preparatory studies and consensus processes are needed.

Relevance for users and families:

This preliminary SMA-ICF-Core Sets may serve as a clinical-decision-making-tree, that supports a better standard of care for infants with SMA.

Supports a holistic perspective, encompassing the multifaceted development of infants, and the environmental factor needed for its thriving.

Underlines the need for an international, age-appropriate, phenotype-specific Core-Sets in pediatric.

Real life study of the implementation of innovative therapies in symptomatic patients with SMA: description of the new phenotypes induced by SMN restoring therapies

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Introduction: Spinal Muscle atrophy (SMA) due to deficiency in Survival of Motor Neuron (SMN) protein is the most frequent genetic cause of death in childhood. SMN restoring therapies recently accessed the market. The implementation of innovative molecules challenges the local organization of care. The long term survival of patients with the most severe forms generate new clinical phenotypes of SMA requiring life-long medical care with a high level of expertise whereas no evidence is available in the literature.

Material and Methods: Descriptive retrospective study of patients followed in a neuromuscular disease reference center between 2012 and 2022.

Results: Over this period, 139 patients were seen at least once. While 25 patients died over the period (90% type 0 and 1), 71 patients were able to start a treatment. At December 1, 2022, 69 SMA patients (respectively 13/35/21 with SMA type 1/2/3) are still under treatment (Risdiplam 45; Nusinersen 20; Zolgensma 4). Among the 11 type 1 treated children [1-8 years], 7 benefit from a nocturnal NIV, 9 patients acquired stable sitting position, 9 eat exclusively by the mouth and all have early progressive scoliosis. Among the 16 type 2 children treated, 3 can stand with support, 1 patient treated at the age of 18 months, acquired walking at 3.5 years.

Discussion: Early Introduction of treatment in symptomatic SMA patients modifies natural history of the disease with the appearance of new phenotypes justifying special attention from Physical and Reabilitation team for the follow-up of these patients.

Relevance for users and families:

High relevance for people with lived experience and their family members to better understand challenges for the orthopedic management

Quality of life in children with Spinal Muscular Atrophy in Greece according to parents and children perspective. Are we entering the new era?

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Introduction: Spinal muscular atrophy (SMA) is an inherited autosomal disease resulting to severe disability and elevated mortality. Just recently we have entered the era of disease modifying treatments and its course is drastically changing. Quality of life is defined as the individual's perception of their living experience related to their health status.

Patients and Methods:A total of 53 children (out of 60-65 patients in Greece) with SMA of all types, aged 0-18, and their parents participated in a survey using the Pediatric Quality of Life Inventory 3.0 Neuromuscular Module (PedsQL NMM).

Results: Parents scored a total of 63.90 in PedsQL NMM and children scored 64.63 resulting in moderate affected QoL. Although there are differences mentioned in scores according to SMA type, there is only statistically significant difference according to mobility status between non sitters and walkers (F2,50=5.567 sig=.006 and F2,22=6.220 sig=.007 respectively). According to children's perspective there is also statistically significant difference between types SMA I and II to SMA III (sig= .023 and .031). A strong positive correlation is observed between parents' and children's responses (r=0.793, sig=.000). Outstandingly 90.6% of the children have been receiving at least one disease-modifying treatment already.

Conclusion: In Greece most of the children with SMA have already access to the innovative disease-modifying treatments and this has a strong positive impact in their QoL and their functioning. There is also a tremendous positive impact in their functional status and 75.5% are sitters or even walkers.

Relevance for users and families:

The study's Results provide an estimation of QoL of children in Greece for the first time. SMA type is not the crucial factor affecting the QoL any more according to parents' perspective, since new treatments have improved both survival and functioning and have raised hope. The study suggests that the role of Physical Therapy has to move towards a more proactive rehabilitative approach to keep up with the new advancements in the QoL of SMA.

Arthrogryposis Multiplex Congenita in pediatric age: correlation between MUScular MRI and functional Evaluation (AMUSE), towards a biomechanical model

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Introduction: Arthrogryposis Multiplex Congenita (AMC) is a group of diseases with joint limitations at two or more distinct joint levels at birth. Joint limitations are not progressive, but the functional consequences have a lifelong impact on patients. The management of AMC is therefore demanding, necessarily multidisciplinary and is a long-term process. The aim of this monocentric retrospective observational study was to evaluate the correlation between muscle fat infiltration and activity deficits and limitations in children with AMC.

Methods: Patients under 18 years of age and/or over 18 years of age with exclusive pediatric follow-up evaluated at the AMC Reference Centre of the University Hospital of Grenoble Alpes between 2010 and 2022 were included. Patients underwent a multidisciplinary assessment including whole body MRI. Muscle fat infiltration was quantified using the MERCURI score.

Results: We included 97 patients, 50% had Amyoplasia, 38% had Distal Arthrogryposis (DA) and 12% from group 3 “other”. We showed that the Mercuri score was significantly correlated with muscle weakness and PROM in the upper and lower limbs in Amyoplasia and in DA and only for the lower limbs in group 3 “other”. Furthermore, in Amyoplasia and in DA, the Mercuri score was also correlated with reaching ability.

Conclusion: Our study is one of the first in a pediatric population to investigate the link between muscle imaging and functional aspects of AMC. Muscle MRI is a recommended tool for diagnosis, but it is also a suitable non-invasive tool to assess and assist in the functional prognosis of patients.

Relevance for users and families:

These first Results of our studies will allow us to develop a predictive model of the functional prognosis of patients in order to better adapt their multidisciplinary management and improve their functional capacities.

The aim will be to build a reliable biomechanical predictive model to assist in therapeutic decision making and to allow adapted and personalized management of patients and anticipate their health needs.

Gross motor development by age and GMFCS level in children with cerebral palsy - a Norwegian population-based registry study

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Introduction: Motor Development Curves and reference percentiles for GMFM-66 are valuable tools for following, predicting, comparing and evaluating changes in gross motor function in children with cerebral palsy. We here create motor development reference percentiles curves based on Norwegian data, and compare them with Hanna et al. 2008.

Method: We applied prospective population-based cohort data from the Norwegian Quality and Surveillance Registry for Cerebral Palsy (NorCP). Participants were 1009 children with totally 3127 GMFM-66 tests. The distribution of GMFM-66 by age was modelled by a normal distribution with smoothing splines fixing location, scale and added skewness. To adjust for repeated individual measurements, we report the median curve of 100 samples with random one observation per child.

Results: The estimated GMFM-66 percentiles by age are similar to the earlier reported Canadian percentiles, with only minor differences.

Conclusion: The existing Canadian reference curves are also valid for newer European data from Norway, and will likely work well for both clinical and research applications.

Relevance for users and families:

While the GMFM-66 total scores show the child's gross motor skills and can tell if the child has learned new gross motor functions, the reference percentiles can tell whether the change is more or less than what is expected for children of the same age and GMFCS level.

Mini-Symposium: Treating speech motor abilities in children with Cerebral Palsy: the PROMPT motor speech treatment

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Objectives. To present research and clinical-based perspectives on speech motor treatment for children with Cerebral Palsy (CP).

Summary: This multidisciplinary team will provide an up-to-date perspective on evidence-based intervention to support motor speech performance in CP, and in particular PROMPT treatment will be described as a model for speech motor treatment in CP. Preliminary Results from a clinical trial on speech motor treatment with PROMPT will be presented. A kinematic analysis of speech motor abilities will be introduced in relation to the method applied in the clinical trial. A family perspective on the speech motor intervention clinical trial is included.

Outline of the symposium:

- Introduction of speakers and aims of the symposium (5 mins Andrea Guzzetta/Giuseppina Sgandurra)
- Speech motor profile in Cerebral Palsy (10 mins Carolina Ragoni)
- Treatment options for speech motor disorders in CP (15 mins Irina Podda)
- A clinical trial on PROMPT motor speech treatment in CP (15 mins Simona Fiori)
- Kinematic analyses of speech movements in the pediatric setting (15 mins Marco Pirini)
- The family perspective on a clinical trial to improve speech motor abilities in CP (15 mins Silvia Busetto)
- Panel discussion (15 mins)

Relevance for users and families:

Evidences from a clinical trial support the hypothesis that speech motor treatment may substantially improve speech abilities in children with CP, with a potential impact on personal autonomies, communication and quality of life. Speech motor treatments have a potential to impact on long term outcome of children with CP according both to clinicians and families.

Oral Communication: Participation

Assessing participation in adolescents with cerebral palsy: comparison of Life-Habits and USER-Participation

Gerjanne Van Alphen[2,4], Marjolijn Ketelaar[1,2,3,5], Jeanine M.Voorman[1,2,3,5,7], Eline W.M. Scholten[1,2,3,5], Marcel W.M. Post[1,2,3,5,6]

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Introduction: To explore and compare the contents and scores of the Assessment of Life-Habits (Life-H) with the Utrecht Scale for Evaluation of Rehabilitation-Participation (USER-Participation) in adolescents with cerebral palsy (CP).

Methods: Youth versions of both instruments were used for (1) content comparison and (2) analyses of relations between both instruments, based on cross-sectional data. Participants were adolescents with CP, aged 12-18 years; GMFCS I-V; N=45.

Results: Both instruments measure independence in participation, called accomplishment (Life-H) and restrictions (USER-Participation), and satisfaction with participation. Life-H comprises 6 domains (Responsibilities, Interpersonal relationships, Community life, Education, Employment and Recreation) and the USER-Participation 3 (Productivity, Leisure and Social).

Compared with the USER-Participation, the Life-H contains more specific items, more items not-applicable to many participants and more ceiling effects. Total scores on the accomplishment/restrictions and satisfaction scales between both instruments showed strong correlation coefficients (0.87 and 0.67, respectively). Correlations between domain scores were stronger within the accomplishment/restrictions scales (range 0.37-0.88) compared with the satisfaction scales (range 0.22-0.68).

Conclusions: Compared with the USER-Participation, the Life-H takes more effort to complete but provides a more comprehensive assessment of participation. Participation accomplishment/restrictions scores were more similar between the instruments compared with satisfaction scores. Researchers and clinicians should carefully compare participation instruments in selecting one that matches their purpose.

Relevance for users and families:

Relevance for users and families: Questionnaires on participation, especially those including satisfaction as an important element of participation, will support adolescents and health care professionals in shared goal-setting and evaluation of goals after rehabilitation interventions.

Factors impacting positive and negative participation of young people with cerebral palsy: A Delphi study of consumers and health professionals.

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Introduction: To obtain consensus on the most important factors impacting positive and negative participation experiences of young people with cerebral palsy (CP).

Patients and Methods: A three-round Delphi survey study design was used. Consumers (young people with CP and caregivers) and health professionals were asked to generate and then rate items influencing positive and negative participation experiences. Qualitative content analysis and descriptive statistics were used to classify items across the family of Participation Related Constructs (fPRC) framework.

Results: Sixty-eight participants completed Round I (25 consumers, 43 health professionals).

Round II resulted in a consensus for all but two items, with Round III not required. The fPRC construct with the most items rated as extremely important for positive participation experiences was Environment–Availability, and for negative participation experiences was Environment-Acceptability for both adolescents and young adults.

Conclusion: A consensus was reached on the most important items influencing the positive and negative participation experiences of young people with CP.These items should be prioritised when developing support services and allocating funding to improve the participation experiences of young people with CP.

Relevance for users and families:

This is the first study reporting consumer and professional consensus on factors promoting positive and negative participation for young people with cerebral palsy. Multiple factors were identified that produce positive and negative participation experiences and should be prioritised when developing supports and services. Findings highlighted that ensuring availability of appropriate activities and services is extremely important for enabling positive participation experiences and promoting acceptable attitudes of others is extremely important for alleviating negative participation experiences.

How did youth with cerebral palsy perceive participation in everyday life after participating in a periodical intensive rehabilitation programme based on adapted physical activity ? A qualitative interview study

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Introduction: While many Norwegian youths with cerebral palsy (CP) participate in intensive rehabilitation programmes, few programmes have been evaluated regarding participation outcomes from the perspective of youth. Understanding youths ´experiences of intensive rehabilitation are critical for identifying key successful participation factors.

Patents and Methods: A qualitative design that included semi-structured interviews with 14 youths with CP (mean age 17 years)

Results: Qualitative content analysis exposed six themes, 1. Everyday life – to get the pieces of your life to fit together, 2. Participation means inclusion and belonging – the meaning of life, 3. Individual and environmental factors influencing participation, 4. Experience physical and social activities away from home with like-minded people, 5. To be continued locally, and 6. You do not know the future, anything can happen – visions for the future. Improved ability to participate provided a feeling of belonging and increased meaning in their lives. Being active takes energy; discriminatory attitudes and lack of aid increased participation difficulty, while family and friend support facilitated participation. Competent staff adapted activities and meeting peers were crucial. The participants reported similar hopes for the future as their non-disabled peers

Conclusions: Participation in everyday life increases the meaning of life but takes energy. Periodical intensive rehabilitation programme enabled youths to try new activities, make friends and increase self-insight in their strengths and limitations

Relevance for users and families:

A periodical intensive rehabilitation, including adapted physical activities in groups, is recommended to provide peer learning and mastery experiences in young people with CP.

To build the courage to push individual boundaries in new activities periodical intensive rehabilitation together with peers is preferable

The experiences and perceptions of participation in daily life of adolescents and young adults with cerebral palsy: a scoping review

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Introduction: Young people with cerebral palsy (CP) face increased difficulty in participation during the transition to adulthood, compared to their peers. This scoping review synthesised literature that explored or measured the experiences of participation of adolescents and young adults with CP in major areas of adult life.

Methods: Six electronic databases were systematically searched. Quantitative and qualitative data were extracted and processed using a convergent integrated analysis framework; data analysis was completed using a thematic synthesis approach.

Results: Thirty-four studies with n=1,713 participants were included. Young people with CP described their experiences of participating in adulthood around the major theme of 'getting to know myself.' Key elements of this were: becoming who I want to be, developing my independence and 'doing' the same as my peers, learning about my body, exploring my sexuality, determining what I need from healthcare providers, and building my community. Crucial, supportive environmental elements were those people in the 'circle of support,' and provision of day-to-day assistance. Navigating healthcare and disability or social services, major knowledge gaps, and community prejudice were highly negative experiences in pursuing participation in this life stage.

Conclusion: A greater emphasis on supporting young people with CP to understand their bodies, sexuality, and the changing relationship with family, is needed to reduce the unknown and optimise participation during early adulthood. There is also critical need for healthcare providers with expertise in adult CP, and disability services that are user-friendly, focused on facilitating successful transition to adulthood, and enabling participation in this group.

Relevance for users and families:

Young people with CP who are transitioning to adulthood express their desire to participate across all major areas of adult life, alongside their peers. The findings of this review should encourage families as well as health care and education providers to engage with young people with CP on sensitive topics pre-emptively, and with openness. The importance of mentors and role models who have CP is also highlighted as a key facilitator to participation.

Participation and BEYOND: The benefits of environment-based approaches among young people with physical disabilities

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Introduction: Personalized 'top-down' approaches such as the PREP (Pathways and Resources for Engagement and Participation) are considered recommended practice to improve participation of youth and young adults with physical disabilities. However, their impact on a range of outcomes has not been established. Project BEYOND (Body-function Enhancement for YOuth through participatioN in real-worlD contexts) further examined the effects of PREP on changes in 1) participation performance and satisfaction, as well as the factors that affect these changes, and 2) three body functions outcomes: motor, cognitive, and affective.

Patients and Methods: A 22-week interrupted time-series design with multiple baselines across 21 youth with disabilities aged 16-25 (median=21.4) during COVID-19 was employed. The Canadian Occupational Performance Measure assessed participation performance and satisfaction weekly. Mental health problems, as well as affective and cognitive outcomes, were assessed weekly using the Behavior Assessment System for Children, Third Edition. A range of tools was used to assess motor functions (e.g., trunk control, reaching, strength) biweekly. Mixed-effects models were used.

Results: Significant intervention effects were observed in participation performance and satisfaction with large effect sizes (1.36 and 0.98, respectively).Youth falling within the norm, with respect to their mental health, benefited more from the intervention. Improvements in at least one body function outcome were seen among 10 out of 21 youth, especially for motor outcomes.

Conclusions: Findings highlight the potential benefits of 'top-down' approaches that go beyond participation and involve outcomes at the body-function level. Further qualitative studies are warranted to better understand the advantages of such approaches.

Relevance for users and families:

Results can increase awareness of youth, clinicians, and policymakers to the added value embedded in youth-engaging participation-based therapy approaches as they can lead to improvements in other outcomes than those targeted by the intervention

Participation in home-based activities of children with cerebral palsy and type of change desired: Parental perspective

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Introduction: To optimize the participation of children with cerebral palsy (CP), it is important to understand child and parental perspectives on needed changes in different aspects of activities. This study aimed to explore desired types of change in home-based activities from the parental perspective.

Patients and Methods: We performed a secondary analysis of data collected using a hard-copy survey in Serbia. A convenience sample included 110 children with CP aged 7–18 years (61 males; mean age 12.7y [SD 3.4y]; GMFCS I–III=66; IV–V=44). Parents completed the Participation and Environment Measure for Children and Youth (PEM-CY). The distribution of each type of change desired (frequency, involvement, variety) was examined at the activity level and compared within-group using one-way repeated-measures ANOVA.

Results: Higher frequency, greater involvement and a broader variety were the prevailing desired types of change across different home-based activities. Exceptionally, lower frequency and involvement were noted regarding computer and video games and watching TV, videos, and DVDs.

Conclusion: Parents focused on more frequent involvement in home-based activities that involved social interaction and provided children with the opportunity to acquire social skills (getting together with other people; indoor play/games) or learn skills for living independently (household chores; personal care management). Parents also marked a broader variety of activities that required higher levels of manual abilities (arts, crafts, music, hobbies) and communication, cognitive and social abilities (indoor play/games). Our finding indicates that parents are focused more on participation frequency and variety than on the level of the child's involvement in the same activities.

Relevance for users and families:

Children with cerebral palsy often have difficulties engaging in everyday activities, including those that take place in their homes. Participation and its optimization are recognized as relevant outcomes in disability studies. This study aimed to investigate what changes are needed, if any, from the perspective of their parents. Our finding indicates that parents are focused more on the frequency and variety of activities than on the level of the child's involvement in the same activities.

Instructional Course: Knowledge translation through co-creation: Longitudinal data into readable web-based information for children and young people with cerebral palsy, parents and professionals.

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Objective: To learn about the process of knowledge translation and development of a website in co-creation with young people with Cerebral Palsy (CP), their parents, healthcare professionals and researchers, based on a project focusing on scientific knowledge on the development of children and young people with CP.

Learning objectives of the course

- Increase knowledge on the process of knowledge translation in co-creation.
- Build awareness of the value of co-creation and unique perspectives of all involved.
- Describe tools and strategies for knowledge translation in co-creation.
- Identify opportunities to use the tools and strategies in other projects.

Target audience: Researchers and healthcare professionals working in the field of research or healthcare innovation and individuals with lived experience of disability and their families.

Summary: This is an interactive course on knowledge translation of the longitudinal PERRIN study on the development of children and youth with CP in co-creation with people with CP, parents, professionals and researchers. Opportunity to learn strategies for translating scientific information into easily readable web based information and demonstration of the website as an example of knowledge translation. Strategies learned during the course can be used for other projects and different diagnostic groups.

Outline of the course

- Introduction of topic and learning objectives of the audience
- Knowledge translation of longitudinal data on cerebral palsy based on the PERRIN study.
- Tools and strategies for developing web based information in co-creation.
- Highlighting perspectives of co-creators and lessons learned.
- Interactive discussion with the audience.

Relevance for users and families:

This instructional course will give people with lived experience insight in the role they can have in a knowledge translation and co-creation process. The course will empower young people with CP and parents to work together in knowledge translation with healthcare professionals and researchers. A step by step example, including practical tools, is given by using the longitudinal PERRIN study on the development of activities and participation in children, youth and young adults with CP.

Mini-Symposium: Improving the Health and Well Being of Adults with Cerebral Palsy: International and Personal Perspectives.

Mark Peterson[1], **Emma Livingston**[2], **Jennifer Ryan**[3], **Elisabet Rodby Bousquet**[4], **Jan Willem Gorter**[5]

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Objectives:

- Understand the risk of developing noncommunicable diseases including mental health outcomes in adults with CP.
- Describe the pain phenotype and treatment disparities faced by adults with CP.
- Define issues pertaining to unmet rehabilitation and medical needs in adults with CP globally.
- Expand upon advocacy efforts that improve stakeholder engagement in clinical care and research

Summary:

This symposium will integrate information based on research about secondary physical and mental health complications of chronic inactivity from the U.S. and Europe, and work pertaining to health status and unmet rehabilitation needs globally.

Outline of the symposium:

Chair Introduction: Mark D. Peterson; 10 minutes

- Understanding the unique healthcare needs of adults living with CP in the United States

Presenter: Emma Livingston; 15-20 minutes

- Adult CP Hub-Lived Experience
- National and global advocacy

Presenter: Elisabet Rodby Bousquet; 15-20 minutes

- Physical health and social outcomes in adults with cerebral palsy living in Sweden
- Implementing multi-professional health care programs for adults with cerebral palsy

Presenter: Jennifer Ryan; 15-20 minutes

- Worldwide prevalence and incidence of chronic conditions among adults with cerebral palsy
- Unmet health needs among young adults with cerebral palsy in Ireland
- Health service use and unmet needs among adults with cerebral palsy in Ireland

Presenter: Jan Willem Gorter; 15-20 minutes

- New findings pertaining to the long-term cardiovascular and mental health outcomes in CP.
- Understanding brain function as relates to well-being in adults living with CP.

Q&A and Audience Interaction; 15 minutes

Relevance for users and families:

Rehabilitation needs and care coordination in adults with CP will be a central focus of this symposium. In addition, viable interventions that may lessen the functional deterioration due to aging with CP will be discussed. This symposium will bring together researchers across four countries and the personal perspectives of lived experience focusing on new and challenging issues facing adults with CP.

Mini-Symposium: Together against (and IN) pain: collaborative child-parent-professional approaches in preventing and managing pain in children with cerebral palsy

Hrvoje Gudlin[3], **Monika Novak-Pavlic**[1,2], **Darko Milaščević**[4]

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Objectives:

- To learn about the specifics of pain in children with cerebral palsy (CP) and its implications on participation and quality of life
- To learn about the state of evidence and best practices for preventing and managing pain in children with cerebral palsy
- To learn about the factors and coping strategies associated with pain in children with CP
- To understand the multidimensionality of the concept of pain in children with CP

Summary: Children with CP are believed to experience more pain than typically developing children due to the nature of their condition. However, pain in children with CP is oftentimes unrecognized or misunderstood, whereas pain prevention and management are insufficiently taken into account. In this presentation, we aim to present the research evidence on best practices for pain prevention, assessment and management in children with CP and present how those can be implemented in practice.

Outline: Participants will, together with the presenters, discuss their experiences with preventing and treating pain in children with CP and reflect on current practices for pain management. We will present some practice case examples - how pain can holistically be assessed, prevented and managed – and how different painful conditions interfere with everyday functioning of a child and family. Case examples of children experiencing pain will be demonstrated using the principles of problem-based learning. Through video-based analysis, professionals will become more aware of the complexity of pain and its implications, as well as how pain can be discussed during treatment planning and parent coaching.

Relevance for users and families:

This presentation would be of interest to children with CP, their caregivers and professionals working with children with CP. We are hoping that through the information presented in this symposium, attendees will be better equipped with knowledge on the pain management practices and get ideas on how and why pain assessment and prevention can be integrated in rehabilitation practices for children with CP.

Mini-Symposium: Neonatal neuroimaging and later cerebral palsy - a consensus on classification for CP registers and its application

Veronka Horber[1], **Javier De La Cruz**[2], **Kate Himmelmann**[3,4], **Daniel Virella**[5,6]

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Objectives: The aim of this mini-symposium is to introduce participants to a classification system for neonatal neuroimaging Results (cranial ultrasound and MRI) for CP registers indicating a risk for cerebral palsy (CP). By the end of the symposium, it is expected that participants will understand the need for such a classification, and how it was developed and evaluated. Implementation features that are described in a detailed companion manual will be illustrated in open discussion with the audience.

Summary: After having established a classification system for neuroimaging Results in the older child with CP, MRICS, Surveillance of Cerebral Palsy in Europe (SCPE) aimed at extending the work with a classification system for neonatal neuroimaging Results for use in CP registers.

The neonatal neuroimaging classification system (NNICS) was developed with neonatal imaging experts and, as for MRICS, intended to describe pathogenic patterns occurring in different periods of brain development and to illustrate these patterns in a detailed manual. NNICS describes 5 main groups: brain maldevelopments, predominant white matter injury, predominant grey matter injury, miscellaneous and normal findings. An additional neonatal item concerning involvement of the posterior limb of the internal capsule was introduced. NNICS showed good inter-observer agreement, it was considered simple to use and its availability grew continuously to over 30% of children in CP registers.

Outline: NNICS, a classification system for neonatal neuroimaging Results (cranial ultrasound and MRI) for use in CP registers.

Background and concept

- Development of NNICS
- Typical patterns, limitations
- Application, availability

Relevance for users and families:

The Surveillance of Cerebral Palsy in Europe collaboration (SCPE) has developed over time a common language to describe children with cerebral palsy in CP registers. Classification systems previously developed by SCPE on CP subtype and neuroimaging findings in the older child are widely used beyond CP registers and facilitate communication between professionals and with families. In the present

work, SCPE developed and evaluated a classification system for neonatal neuroimaging Results indicating a risk for CP.

Mini-Symposium: Functional and biomechanical changes induced by early Hand-Arm Bimanual Intensive Therapy Including Lower Extremities in pre-school children with bilateral cerebral palsy

Rodrigo Araneda[1,2], **Josselin Demas**[3,4], **Adélie Christiaens**[3,5], **Sandra Bouvier**[6], Mickael Dinomais[3,5], Christopher John Newman[7], **Sylvain Brochard**[6,8,9,10], **Yannick Bleyenheuft**[1]

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Objectives: This mini-symposium aims to present new evidence obtained from a multi-center randomized trial evaluating the effects of Hand-arm Bimanual Intensive Therapy Including Lower Extremities (HABIT-ILE) in 60 pre-school children with bilateral cerebral palsy (CP).

Summary: While many therapies developed over the last 20 years for children with CP have focused on children with unilateral CP, HABIT-ILE applies concepts of motor skill learning and intensive training, stimulating constantly the UE and LE for several hours each day over a 2-week period. Therefore it seems particularly adapted to children with bilateral CP. The effects of HABIT-ILE have been established in school-age children, but have never been evaluated in a large sample of toddlers and infants. During this symposium, Pr. Yannick Bleyenheuft will display significant changes on motor and functional assessments. Pr. Rodrigo Araneda will present the non-motor effects observed following HABIT-ILE, including visuospatial and cognitive changes. Sandra Bouvier will introduce the Results on om movement changes, actimetry, comparing amount of movements performed during this intensive intervention compared with usual motor activity and Josselin Demas and Adélie Christiaens will present the cortical changes associated, as detected through EEG. Pr. Sylvain Brochard will moderate the session.

Outline of the symposium

The functional and biomechanical changes observed as a result of the intensive HABIT-ILE rehabilitation process are likely to affect the children's motor and functional ability, as well as his/her activity and participation level. This may induce possible modifications of the whole developmental trajectory of infants with bilateral CP.

Relevance for users and families:

HABIT-ILE effects have been established in school-age children, but have never been evaluated in a large sample of toddlers and infants with bilateral CP. At this age, positive changes produced by this intervention could be much more important, affecting the trajectory of their development and contributing to their future autonomy impacting so their families

Mini-Symposium: Powered mobility: Facilitating participation in children with Spinal Muscular Atrophy (SMA)type I. Ready for the race?

Rocío Palomo[1], **Beatriz de Andrés**[2], **Lisbeth Nilsson**[3], **Maribel Ródenas**[4]

[1]University Of Castilla-la Mancha, Toledo, Spain, [2]RIE center, Madrid, Spain, [3]Organisation Department of Health Sciences, Lund University, Lund, Sweden, [4]APSA association, Alicante, Spain

Objectives: The symposium will provide the know-how about powered mobility use in children with Spinal Muscular Atrophy Type I. Define what are the barriers of their mobility and how powered mobility can facilitate participation and social interaction. Disseminate the importance of family involvement in early powered mobility through the use of adapted motorized devices supporting development of functional strategies that improve the child's access to their natural environment.

Summary: Children diagnosed with spinal muscular atrophy (SMA) have motor disorders that affect their mobility, restricting activities of daily living and participation. Powered mobility when used within their natural environment, involving the family, can encourage their motivation to be mobile and facilitate participation. Experiences of self-produced mobility gives opportunities for learning and interaction and facilitates autonomy. The child's exploratory activity with an adapted powered device causes continuous changes of position in relation to the physical and social environment, giving new perspectives and opportunities for interaction and participation.

Outline of the Symposium

-Introduction 5'. De Andrés B.

-What are the barriersin the participation of SMA type I in the natural environment? What do the families think? 15'. Ródenas M and Palomo R.

-What can powered mobility offer in SMA type I? Ready for the race? 25' Ródenas M, De Andrés B, Palomo R.

-Why is Driving to Learn a powerful developing experience? How to apply the two parts of the process-based Assessment of Learning Powered mobility use (ALP)? 30'. Nilsson L.

-Discussion. 15'

Relevance for users and families:

We will present information on the direct interaction between families and researchers and the importance of involving families in environment-directed therapy and in the development of research through "Family Engagement in Research", developing a questionnaire to detect the barriers that hinder power mobility in the natural environment.

Mini-Symposium: New frontiers for the use of Artificial intelligence in unilateral cerebral palsy: The AInCP European project

Giuseppina Sgandurra[1,2], Giuseppe Prencipe[1], Silvia Filogna[1], Elena Beani[2], Roslyn Boyd[4], Alex M. Pagnozzi[5], Simona Fiori[1,2], Andrea Guzzetta[1,2], Laura Biagi[2], Francesca Fedeli[6], Gemma D'Alessandro[6], Ain CP Consortium, Alexandra Kalkantzi[1], Giovanni Cioni[1],

[1]University of Pisa, Pisa, Italia, [2]IRCCS Fondazione Stella Maris, Pisa, Pisa, [3]KU Leuven, University of Leuven, Leuven, Belgium, [4]Queensland Cerebral Palsy and Rehabilitation Research Centre, Centre for Children's Health Research, Faculty of Medicine, The University of Queensland, Brisbane, Queensland, Australia, [5]The Australian e-Health Research Centre, Commonwealth Scientific and Industrial Research Organisation, Brisbane, Queensland, Australia, [6]FightTheStroke, Milan, Italy

Objective: This symposium will provide the know-how about the AInCP project and specifically on the application of artificial intelligence methodology for establishing a clinical phenotyping, analyzing advanced brain imaging and real-life monitoring of upper limb function with the ultimate goal to build personalized diagnostic, rehabilitative and theranostic decision support tools in children with unilateral cerebral palsy (UCP). Moreover, we will stress the crucial role of families in the research activities is to achieve the innovative co-design approach of AInCP .

Summary: Unilateral Cerebral palsy (UCP) is the most common neurological chronic disease in childhood with a significant burden on children, their families and the health care system.

AInCP is a 5-year European project, involving 11 partners coming from 5 European countries (Italy, Spain, Belgium, Austria, The Netherlands) and Australia, financed within the Horizon Europe framework (GA 101057309), that aims to develop evidence-based clinical Decision Support Tools for personalized functional diagnosis, Upper Limb assessment and home-based intervention for children with UCP, by developing, testing and validating trustworthy artificial intelligence and cost-effective strategies.

Outline:

- General Introduction: Prof. G. CIoni (5')
- The AInCP project: the "fusion" between clinicians and data scientists G. Sgandurra, G. Prencipe, S. Filogna (15')
- Clinical study: R. Palomo, L. Mailleux, E. Beani (10')
- Real life monitoring: S. Filogna, E. Beani G. Prencipe, (10')
- Neuroimaging: R. Boyd, A. Pagnozzi, S. Fiori, A. Guzzetta, L. Biagi (10')
- Co-design with parent's perspective: F. Fedeli, G. D'Alessandro (10')
- Discussion 30'

Relevance for users and families:

We will provide an example of a comprehensive and multidisciplinary approach where all project

collaborators (clinicians, data scientists, physicists, engineers, economists, ethicists, SMEs, children and parent associations) are working closely together in building the AInCP approach.

Instructional Course: I see, I move, I participate – understanding the importance of a transdisciplinary approach in (re)habilitation of children with difficulties in visual motor integration

Hrvoje Gudlin[1], **Andrea Paulik**[1]

[1]Mali dom - Zagreb, Zagreb, Croatia

Working with children with disabilities requires an approach in which professionals develop integrative ways to set goals for the child's development. The main purpose of this course is to highlight the importance and utility of a transdisciplinary approach in pediatric (re)habilitation.

In theoretical part different clinical features and levels of visual and motor functioning will be explained, based on VFCS and GMFCS classifications. Practical part encourages participants to experience real - life situations in which vision affects motor performance and vice versa. Together we will learn the importance of thinking about interaction between visual and motor development when planning treatment.

This course is intended for professionals/students in the field of pediatric (re)habilitation, mainly physiotherapists, special education teachers, TVI teachers, occupational therapists. Parents/family members of children with disabilities are welcome in order to understand the importance of a transdisciplinary approach.

Professionals will expand knowledge and creativity in clinical reasoning and goal setting. Parents could recognize their child’s strengths and work on goals in a home environment. Using VFCS and GMFCS classifications, professionals and parents could set realistic goals together and improve the child's overall functioning.

The course has two main parts, each lasting approximately 40 minutes. Theoretical background focuses on gross motor and visual skills classification systems, and is essential for understanding course content. In videos of children with multiple disabilities we will analyze orientation and movement in space, without and with adjustments. Practical part focuses on self – experience of everyday situations, to understand a child's behavior and functioning better.

Relevance for users and families:

Children could recognize their possibilities and be encouraged to use them in everyday functioning, in order to be more successful in their overall functioning, social relations, sport and leisure activities etc.

Family members could then recognize necessary adjustments and provide content-filled environment, so that children can prosper in their natural environment.

Instructional Course: Community-based intensive early intervention - from challenges to empowering

Liliana Klimont-Fjøsne[1], **Anne Kilde**[1], **Monica Berg**[1]

[1]Akershus University Hospital, Dept. Of Pediaric and Adolescent Medicine, section for habilitation, Lørenskog, Norway

Objective:The objective of the course is to present transdisciplinary model of community-based early intensive intervention for children with cerebral palsy and other neurological conditions with GMFCS level III - V. Two main aims of the model are:

- To empower resources around the family and child for goal setting and intervention which promotes and harness communities and families capabilities.

- The implementation of optimal, problem-specific intervention strategies based on ICF-CY framework.

All children participating in the intensive training program were offered 3 periods 4 weeks each of transdiciplinary intensive course. Family, specialists from their community and the rehabilitation department co-operate together with equal commitment. It consist of 50/50 division of human and environmental resources.

Learning objectives of the course:

- Ability to set short-terms goals important for the child and family
- Demonstrate the process of clinical reasoning in the ICF perspective to optimize activity and participation
- Demonstrate the importance of work together across disciplines and empowering through knowledge transfer between the professionals and «key-persons» around the child
- Demonstrate implementation of modifications, and task-specific training in the child`s natural environment

Target audience: Families, professionals concerned with care of infants with cerebral palsy and similar conditions, physiotherapists, occupational therapists, speech and language therapists, multi-disciplinary teams encouraged to attend together.

Summary: Proposed community-based early intervention/treatment model resulted in better understanding of the individual needs and helped to create «specific to the problem» interventions. Putting the “spot-light” equally on the child and «key persons resulted in empowering the environmental resources.

Relevance for users and families:

Reinforcement of common understanding of child`s and family`s needs within ICF domains.Empowering and enhancement of families, professionals and caregivers across different care levels in a long-term perspective.

Instructional Course: Standardized Infant Neuro Developmental Assessment – an easy and quick tool to detect infants at high risk of neurodevelopmental disorders

Mijna Hadders-Algra[1], **Uta Tacke**[2], Joachim Pietz[3], Heike Philippi[4]

[1]University Medical Center Groningen, Groningen, Nederland, [2]University Children's Hospital (UKBB),, Basel, Switzerland, [3]Palliative Care Team for Children and Adolescents, Frankfurt, Germany, [4]Centre for Child Neurology, Goethe University, Frankfurt, Germany

Objective: Presentation of the Standardized Infant NeuroDevelopmental Assessment (SINDA), so that clinicians can start to implement SINDA in clinical practice.

Learning objectives of the course:

- To gain knowledge about SINDA, its design, psychometric properties and clinical applicability

- Capacity to apply SINDA in clinical practice with the help of SINDA's manual and accompanying >160 videoclips

Target Audience: Clinicians, including (neuro)paediatricians and paediatric physiotherapists, working in the field of early detection and early intervention of neurodevelopmental disorders.

Summary: SINDA is a novel neurodevelopmental assessment for infants of the corrected age of 6 weeks to 12 months. It has three scales: a neuromotor scale (28 dichotomous items – independent of infant age), a developmental scale (15 dichotomous items/months) and a socio-emotional scale (6 dichotomous items – independent of infant age). The course will address SINDA's design, its applicability and psychometric properties. The latter include the presence of norm-referenced data per item, a good reliability and good validity (for instance, prediction of cerebral palsy: sensitivity 91-100%; specificity 81-85%). The course will be richly illustrated by video-examples. It will include an interactive practice part (scoring of video examples) and it will allow ample time for discussion.

Relevance for users and families:

Users learn to apply SINDA which assists early detection of infants at high risk of neurodevelopmental disorders. Early detection of infants at high risk of neurodevelopmental disorders is highly relevant for families as it allows for intervention from early age onwards. Early intervention is associated with improved infant and family outcomes.

Instructional Course: Lessons learnt from the REACH Rehabilitation Early for infants at high risk of Congenital Hemiplegia – informing clinical practice and future research

Roslyn Boyd[1], Susan Greaves[2], Leanne Sakzewski[1], Jill Heathcock[3], Kimberley Scott[4]

[1]Queensland Cerebral Palsy Research Centre, Brisbane, Australia, [2]Royal Children's Hospital, Melbourne, Australia, [3]The Ohio State University, Columbus, USA, [4]Creighton University, Omaha, USA

Aims: This instructional course focuses on two early approaches to upper limb rehabilitation for infants at high risk of unilateral cerebral palsy (UCP). Workshop members have tested the efficacy of modified constraint-induced movement therapy (Baby-mCIMT) and bimanual therapy (Baby-BIM) in a large, single-blind randomised trial in Australia and USA. Objectives: Intervention aimed to improve unimanual and bimanual hand use, and commenced from 3-9 months corrected age (c.a.) up till 12-15 months c.a. It was provided as a home-based program using a coaching model with caregivers. The REACH trial included 96 infants at high risk of UCP.

Target audience: Early interventionists and researchers

Workshop outline:

- Highlight entry criteria for early upper limb rehabilitation for infants at high risk of UCP including early identification tools (General Movements Assessment, Motor Optimality Score (MOS), asymmetric brain lesions on MRI, early asymmetries (MOS, Hammersmith Infant Neurological Exam) and the Hand Assessment of Infants (HAI). (RB)
- Describe the two upper limb interventions including commencement at the correct level of ability and incrementation of the program using the HAI. (SG)
- Describe how the interventions were implemented in the home including use of a caregiver coaching model (SG)
- Present case studies for discussion of Baby-CIMT and Baby-BIM for infants with UCP. (RB,SG).
- Explain measurement of fidelity of delivery of intervention by therapists and enactment of intervention by parents. (KS,JH).
- Discuss trajectories of upper limb unimanual and bimanual hand abilities in infants on the HAI and implications for CIMT or BIM. (LS)

Relevance for users and families:

The REACH clinical trial provided very early intervention for families of children identified as high chance of unilateral cerebral palsy.Two infant friendly approaches (baby-CIMT and Baby-BIM) were delivered to families in the home trained by Allied Health clinicians using a coaching model.The emphasis of the workshop is on the lessons learned from working with families including fidelity of therapist delivery and also parent enactment of the interventions.

Oral Communication: Advances in Management of Orphan Diseases 2

Contribution of mid-level visual processes to face and pattern recognition in individuals with cerebral visual impairment

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Introduction: Cerebral visual impairment (CVI) is increasingly being recognized as a comorbidity in many individuals with cerebral palsy and other neurodevelopmental disorders. Evidence suggests that both face and object recognition may be impaired in individuals with CVI. However, the potential contribution of mid-level visual processes is unclear, making it challenging to identify whether (re)habilitation efforts should be focused on high- or mid-level aspects of visual perception.

Patients and Methods: 12 participants (mean 17.67 years, 5.28 s.d., 9 F) with a diagnosis of CVI and good visual acuity completed a series of computerized assessments including a face recognition task, a glass pattern task, and the L-POST. Spearman rank partial correlations adjusting for age and verbal intelligence scores were run to investigate potential contribution of mid-level visual processes from the L-POST on face and pattern recognition.

Results: Significant correlations between the face perception task and the L-POST overall score were observed ($r = -0.65$, $p = 0.04$). Specifically, we observed significant correlations between contour integration, figure-ground segmentation, texture perception, and performance on the face recognition task. Significant correlations were also found between contour integration and performance on the glass pattern task ($p < 0.05$).

Conclusion: These Results suggest that impairments on face and object recognition tasks may be due in part to co-occurring difficulties with contour integration, texture perception, and figure-ground segmentation. This has potential implications for the creation and implementation of efficacious (re)habilitation strategies for improving these key ventral visual stream functions.

Relevance for users and families:

Families and caregivers of children with cerebral visual impairments often report difficulties knowing which intervention strategies should be implemented. By better characterizing which aspects of vision are impacted in an individual child with CVI, more targeted interventions can be implemented. The Results from this study provide evidence that challenges with face and pattern recognition may co-occur with difficulties with mid-level visual processes. Therefore, (re)habilitation programs should include efforts specific to training mid-level visual skills.

Lesion size and long-term cognitive outcome after pediatric stroke: A comparison between two techniques to assess lesion size

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Background: There is little consensus on how lesion size impacts long-term cognitive outcome after pediatric arterial ischemic stroke (AIS). This study, therefore, compares two techniques to assessed lesion size in the chronic phase after AIS and determined their measurement agreement in relation to cognitive functions in patients after pediatric stroke.

Patients and Methods: Twenty-five patients after pediatric AIS were examined in the chronic phase (>2 years) after AIS in respect to intelligence, memory, executive functions, visuo-motor skills, motor abilities, and disease-specific outcome. Lesion size was measured using the ABC/2 formula and segmentation technique (3D Slicer). Correlation analysis determined the association between volumetry techniques and outcome measures in respect to long-term cognitive outcome.

Results: The measurements from the ABC/2 and segmentation technique were strongly correlated ($r = .878$, $p < .001$) and displayed agreement in particular for small lesions. Lesion size from both techniques was significantly correlated with disease-specific outcome ($p < .001$) and processing speed ($p < .005$) after controlling for age at stroke and multiple comparison.

Conclusion: The two techniques showed convergent validity and were both significantly correlated with long-term outcome after pediatric AIS. Compared to the time-consuming segmentation technique, ABC/2 facilitates clinical and research work as it requires relatively little time and is easy to apply.

Relevance for users and families:

The relevance for users is hat the study showed that the rapid ABC/2 technique to of the lesion size is as valid as the more complex segementation method to measure lesion size.

Efficacy of infant friendly Baby-CIMT and Baby-BIM in a randomised trial of home-based parent delivered early intervention for infants at risk of unilateral cerebral palsy

Roslyn Boyd[1], Leanne Sakzewski[1], Jenny Ziviani[1], Sue Greaves[2], Iona Novak[3], Nadia Badawi[3], Margaret Wallen[4], Cathy Morgan[3], Catherine Elliott[5], Ann-Christian Eliasson[6], Jill Heathcock, Andrea Guzzetta[8], Jane Valentine[5], Natalie Maitre[9],

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Introduction: Efficacy of constraint-induced movement therapy (Baby-CIMT) or bimanual therapy (Baby-BIM) to improve upper limb function in infants at risk of unilateral cerebral palsy (UCP).

Study design: Single-blind randomised comparison trial

Study participants & setting: Inclusion criteria: (i) asymmetric brain lesion AND (ii) absent fidgety General Movements (12-16wks post-term age) OR (iii) sub-optimal Hammersmith Infant Neurological Examination, AND (iii) Hand Assessment of Infants (HAI) >3 asymmetries and (iv) 3-9months corrected age C.A. at entry.

Materials/Methods: After baseline assessments, infants were randomised (stratified by age). Both interventions comprised 6-9 home visits and 6-9 telehealth sessions coaching caregivers to deliver the intervention. Daily dose was 20mins (3-6months), 30mins (6-9months) and 40mins (9-15months), 5 days/week over 24weeks.

Results: 96 infants, 51 male, 52 right hemiplegia, born at mean gestational age 35 (±5.3) weeks were randomised to B-CIMT (n=46) or B-BIM (n=50) commenced intervention at mean age 6.45 (±1.58) months. There were no differences between groups on the HAI immediately post intervention (MD 0.98 HAI units, 95%CI -0.94,2.91; p=0.312). Both groups demonstrated significant improvements on HAI post intervention (Baby-BIM MD 3.48 HAI units, 95%CI 2.09-4.87;p<0.0001; Baby-CIMT MD 4.42 HAI Units, 95%CI 3.07-5.77;p<0.0001). At 24 months, 64 infants had UCP (35 B-CIMT, 29 B-BIM), 14 did not have CP (7 B-CIMT, 7 B-BIM) and 8 had bilateral CP (2 B-CIMT; 6 B-BIM).

Conclusions/significance: Baby-CIMT and Baby-BIM were both effective in improving uni and bimanual hand-use in infants at high risk of UCP.Both approaches demonstrated significant improvements in hand development over time.

Relevance for users and families:

Parents with infants at high chance of unilateral Cerebral Palsy can be identified early prior to 6 months corrected age and fast tracked to specific early neuro-rehabilitation.Infant friendly approaches to early intervention such as modified Constraint Induced Movement Therapy (Baby-CIMT) and modified bimanual therapy (Baby-BIM) are both effective at improving uni and bimanual hand skills when delivered as a home based program delivered by the parent trained by therapists using a coaching model.

Development and psychometric properties of the Upper Limb-Motor Learning Strategy Tool (UL-MLST) for children with cerebral palsy

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Introduction: Underpinning almost all task-focused models of upper limb therapy for children with cerebral palsy (CP) are concepts from motor learning theories. However, the concepts have been described as a topic that is not yet fully understood in clinical practice and requires specific training. Therefore, we have developed an Upper Limb-Motor Learning Strategy Tool (UL-MLST) to guide clinicians on how to implement motor learning strategies in upper limb models of therapy for children with CP.

Patients and Methods: The UL-MLST includes an Online Training Program, a Manual and a Checklist developed through an extensive literature search, item generation, and content development process confirmed by two experts. Recruiting 21 clinicians, reliability evaluation was embedded in a 3-session Online Training Program. Clinicians were allocated into groups of 7 raters to each rate two videos of the same model of therapy twice (two weeks apart) to evaluate inter and intra-rater reliability of the UL-MLST checklist for 3 models of upper limb therapy. Data was analysed using Gwet's AC1.

Results: All strategies included in the UL-MLST were judged to be valid by both experts. Intra-rater reliability was excellent (0.81) for Goal-Directed Training (GDT) and substantial for Bimanual Therapy (0.76) and modified Constraint Induced Movement Therapy (mCIMT) (0.73). Inter-rater reliability was substantial for both Bimanual Therapy (0.71) and GDT (0.70), but moderate for mCIMT (0.46).

Conclusion: The UL-MLST provides a valid and reliable tool to support clinicians in the implementation of evidence-based upper limb models of therapy for children with CP.

Relevance for users and families:

The UL-MLST provides clinicians with a tool for self-appraising the implementation of motor learning-based therapies supporting their understanding of when, and how to use the strategies to optimise learning in children with CP. It can also be used by observers (e.g., supervisors) to evaluate the application of strategies used by another clinician. This insight allows for criterion-referenced evaluation of individual performance in the delivery of specific strategies, which may warrant adjustment in future therapy sessions.

Reported responses to sensory events in daily life in children with cerebral palsy

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Introduction: Sensory information is important for motor functioning, learning, and participation. The aim of this study was to explore how parents reported that their child with cerebral palsy, CP, responded to sensory events in relation to spastic subtype and motor functioning.

Patients and Methods: In this cross-sectional study, 55 children with spastic CP (unilateral: 18, bilateral: 37), mean (SD) age 12.3 (3.7) years, GMFCS levels: I: 28, II: 12, III-IV: 15, participated. Parents rated their children's behaviors with the norm-referenced questionnaire Child Sensory Profile-2© (CSP-2©), Swedish version, incorporating six sensory and three behavioral sections, providing four sensory processing patterns/quadrants. Scores 2SD above the norm indicate clinically relevant difficulties and high frequency of behaviors. Parametric and nonparametric statistics were used.

Results: On the CSP-2© the children with CP had a significantly higher mean score on all nine sections compared to norm-reference values. In one or more sections, 53 % of the children (n=29) scored 2SD above the norm. The children were distributed accordingly in the sections: auditory 7, visual 3, touch 3, movement 5, body position 22, oral 5, conduct 0, social emotional 10, attentional 8. For the sensory processing patterns/quadrants: seeking 1, avoiding 8, sensitivity 5 and registration 14. With respect to spastic subtype and motor functioning the scores did not differ.

Conclusion: Children with CP have altered responses to sensory experiences in daily life as measured by CSP-2©. In the section of body position, 40% were reported to have clinically relevant difficulties indicating sensorimotor problems.

Relevance for users and families:

The findings of this study focus attention to the complexity of the sensorimotor behavior in CP and warrant the need for diagnose specific instruments to measure responses to sensory events. Our Results indicate that children with CP to a high extent avoid or act bystanders during sensory events in daily life. This emphasizes the importance of individualizing activities to promote exploration, motor learning and participation for all children.

Effectiveness of school-based physiotherapy intervention for children: a systematic review

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Introduction: Despite many children receiving therapy in school settings, the most effective school-based therapies are unknown. This study aimed to identify and evaluate effectiveness of school-based physiotherapy interventions for children in school settings.

Patients and Methods: A systematic review was conducted following PRISMA guidelines. Four databases were searched for papers investigating physiotherapy interventions for children in a school setting, with reported physiotherapy outcomes. Methodological quality was evaluated by the Cochrane Risk of Bias tool (randomised trials) or Risk of Bias in Non-Randomised Studies of Interventions (non-randomised trials) and summarised using the GRADE framework.

Results: Thirteen intervention types (24 studies) met criteria. Strong positive evidence supported treadmill training without bodyweight support (n=1), and upper limb and fine motor interventions (n=2). Moderate positive evidence supported Gross Motor Activity Training with Multimodal Education-Based Therapy (GMAT+MET) (n=2), neurodevelopmental treatment (NDT) (n=2), and rock climbing (n=1). Weak positive evidence supported Addressing Barriers to Participation (n=1), ergonomic health literacy (n=3), GMAT with progressive resistance exercise (GMAT+PRE) (n=1), hippotherapy (n=1), MET alone (n=7), overground gait training (n=2), and treadmill training with partial body-weight support (n=1). Strong conflicting evidence was available for non-immersive virtual reality (n=2).

Conclusion: There is a paucity of research about school-based physiotherapy interventions. Current evidence lends support to several interventions, primarily those with established efficacy in other contexts. However, there is insufficient evidence to properly guide current practice in schools. Future research is needed to develop and test efficacy of physiotherapy approaches in school settings for children of different ages and population groups.

Relevance for users and families:

Families of children receiving school-based physiotherapy can have confidence that most school-based physiotherapy interventions identified in this review are supported by preliminary evidence. Clinicians and researchers are encouraged to perform more school-based physiotherapy research to provide clearer evidence for different interventions, education settings and children of different ages and conditions. When choosing physiotherapy interventions, families can ask their physiotherapist about supplementary evidence from other contexts (e.g., community) that may align with their child's goals.

Oral Communication: Vision

Structural brain damage and visual function classification system in children with cerebral palsy due to periventricular leukomalacia

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Introduction: Visual function is crucial for development and can be impaired by several conditions, particularly prematurity. Prematurity is, in fact, well known to give rise both to ophthalmological disorders and to cerebral visual impairment due to brain damage (mainly periventricular leukomalacia, PVL). This study aims to systematically explore the relationship between type and severity of brain lesion on MRI and "basic" visual functionsand adpative visual functioning in a cohort of children with periventricular leukomalacia.

Patients and Methods: 52 children (17 F and 33 M) with bilateral cerebral palsy and history of PVL were recruited at Stella Maris Scientific Institute in Pisa (Italy). We included data of participants with at least one MRI after the age of three years and an evaluation of basic visual functions (including fixation, following, saccades, nystagmus, acuity, visual field, stereopsis and color perception) and visual function classification system (VFCS)

Brain lesions location and extent were assessed by a semi-quantitative MRI-scale for children with CP. Visual Function classification system (VFCS) was used to classify how children with cerebral palsy usevisual abilities in daily life.

Results: Brain lesion severity strongly correlated with visual function total score (global MRI score p <.001). Moreover, VFCS strongly correlated with global MRI score, hemisperic score and subcortical score (all correlations reported a p value <.001).

Conclusion: Structural MRI is valuable for understanding the relationship between brain lesion severity and basic visual function but also with adaptive visual functioning in children with CP.

Relevance for users and families:

VFCS, Periventricular Leukomalacia, MRI

Visual Function Profiles in Children with Spastic Cerebral Palsy in Relation to Gross Motor Function and Manual Ability

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Introduction: Visual functioning is often impaired in children with cerebral palsy (CP). The aim of the present study was to investigate the visual function profile and its association with gross motor function and manual ability.

Patients and Methods: This study recruited 67 children with spastic CP aged from 4 to 12 years (37 males, 30 females, median age 6 years). The Visual Function Classification System (VFCS), Gross Motor Function Classification System (GMFCS), and Manual Ability Classification System (MACS) were assessed. Pairwise relationships among the three systems were assessed using Spearman's correlation coefficients.

Results: Almost half the children (48%) use the visual function in a consistent way, of whom 14% use self-initiate compensatory strategies in performing vision-related activities (Level II), and 22% need some adaptations to use vision functionally (Level III). Twenty-eight percent of children perform only part of vision-related activities even in very adapted environments (Level IV), and 24% use almost exclusively other sensory modalities (Level V). VFCS levels I-II were classified in 74% of children with unilateral spastic CP. VFCS correlated with GMFCS and MACS ($p<0.01$), however, many combinations of functionality were found.

Conclusion: Visual function profiles in CP can be derived from the VFCS and are related to gross motor function and manual ability in children with spastic CP.

Relevance for users and families:

The adaptation of VFCS provides a more comprehensive functional profile of children with spastic CP and informs families, clinicians, and researchers about the service planning and goal-setting process, according to the level of visual functioning in daily life.

Patient- and parent-reported outcome measures of developmental adaptive abilities in visually impaired children: The Visual Impairment Developmental Autonomy (VIDA) scale

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Introduction: Patient-reported outcome measures (PROMs) are useful participatory research indexes to guide clinical interventions and evaluate their efficacy from patients' and caregivers' perspective. Nevertheless, few tools are available for the pediatric population. Furthermore, albeit severe visual impairment (VI) represents a relatively common cause of developmental disability, few functional outcome measures are available. This paper presents the first Results of the Visual Impairment Developmental Autonomy (VIDA) project, aiming to develop a PROM tool to measure the most relevant aspects concerning everyday adaptive abilities in visually impaired children and adolescents.

Patients and Methods: Twenty-nine families and ten adolescents were involved between December 2020 and April 2021 in the co-design of the VIDA scale, consisting of three rounds based on the Delphi approach. The three rounds were 1) suggestions concerning different adaptive abilities domains, 2) relevance evaluation for each item, and 3) definitive version approval.

Results: Families provided a list of 192 items and assessed their relevance. Items were categorized into 5 adaptive abilities areas (table manners, clothing, personal hygiene, orientation and mobility, socio-affectivity) and into three age ranges. The final 102-item VIDA Scale was obtained.

Conclusion: as a PROM measure, our scale could prove useful both in clinical and research settings, filling a gap in the literature and availability of specific instruments to measure rehabilitation outcomes in VI. The validation of the VIDA scale is ongoing, based on the administration of the scale to a larger cohort together with measures of quality of life and child adjustment to investigate its psychometric properties.

Relevance for users and families:

The questionnaire holds premises to be useful as an outcome measure for a patient-tailored re-habilitation, allowing a constant monitoring of the intervention. Furthermore, it can be filled in both by the patient/parent and by the clinician, providing insight into any difference between the perceived and observed adaptive abilities and difficulties. The questionnaire has, as a final goal, to focus on social inclusion and quality of life of visually impaired children and adolescents.

Challenging executive functions and visuo-spatial memory in navigation: a study on children with ADHD.

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Introduction: The Virtual City™ paradigm (VC™) is a playful and motivating visuo-spatial memory task in navigation, delivered in a controlled laboratory space, where the child is asked to memorize and reach houses within a city projected on the floor (Del Lucchese et al., 2021). Simulating real life scenarios, this paradigm could be informative on which neuropsychological functions, traditionally assessed in the peri-personal space, are challenged during locomotion. The aim of this study was to analyse neuropsychological processes underlying VC™ tasks in school-aged children with ADHD.Patient and

Methods: 28 drug-naïve ADHD children aged 7-13 years (m= 9.3±1.68 yrs) admitted to IRCCS Fondazione Stella Maris were administered the path following condition of the VC™ paradigm. Participants were asked to memorize a given number of houses flickering in sequence while remaining in the starting position and then to reach each target in the correct order walking on the streets. All children also underwent a neuropsychological evaluation assessing executive functions (EFs), visuo-spatial and verbal memory.

Results: When VC™ parameters as spatial span, errors and execution time were correlated with neuropsychological measures, statistically significant ($p<.05$) Results were found not only with visuo-spatial short-term memory but also with working memory and EF measures. Multivariate regression analysis confirmed the involvement of EFs (such as inhibition, planning) in determining VC™ performance.

Conclusion: Results indicate that EFs are recruited beyond short-term memory for accurately performing a visuo-spatial memory task in navigation. EFs allow generating, updating and transforming cognitive maps during locomotion.

Relevance for users and families:

Relevance for users and families: Considering that EFs are specifically challenging for children with neurodevelopmental disabilities, as those diagnosed with ADHD, the VC™ paradigm has proven to be a playful and feasible tool to assess neuropsychological functions recruited in a navigation task as involved in complex real-life situations. These promising Results pave the way for the improvement of such a paradigm for rehabilitative interventions aiming to enhance the neuropsychological processes involved, especially EFs.

Relationships between lower limb tactile function, tactile localisation, and motor-related outcomes in children with upper motor neuron lesions.

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Introduction: Somatosensory function is essential in motor activities and learning in children with upper motor neuron (UMN) lesions. Specific to the lower limbs, somatosensory information is vital for adapting walking steps and maintaining balance. However, as research is lacking, we investigated relationships between tactile perception and body awareness with lower limb selectivity, gait capacity and performance in children with UMN lesions.

Method: We assessed the tactile threshold (TT) with monofilaments and tactile localisation tasks for spatial (TLTaction) and structural (TLTperception) body representation on the foot sole. We determined correlations between the somatosensory function outcomes and the selective control assessment of the lower extremity, the modified timed up and go test, the Gillette functional assessment questionnaire, and the functional mobility scale.

Results: Participants were 40 children with UMN lesions (mean age 11.7 ± 3.4 years). Spearman correlations (rs) showed a fair to good relationship between the TLTperception and selectivity (rs = 0.62, p<0.001), gait capacity (rs = -0.40; p=0.02), and gait performance (rs= 0.56, p<0.001). However, there was little correlation between TLTaction, and the motor-related outcomes and no correlation between TT and the motor-related outcomes.

Conclusion: The high and significant correlation of structural body representation measured with a TLTperception shows a high relationship between this aspect of body awareness and motor-related outcomes. In contrast, there was only a low relationship between spatial body representation and no relationship between TT and motor outcomes. These Results indicate that the brain's additional central processing of somatosensory information influences motor skills more than tactile perception.

Relevance for users and families:

Assessment of lower limb somatosensory function still needs to be included in routine clinical examinations. In particular, assessing structural body representation could identify specific somatosensory impairments in children with UMN lesions. In addition, future studies should investigate the effectiveness of including approaches to improve body awareness in the multidisciplinary therapy program on gait-related functional outcomes.

Comparing visual functions between children with unilateral cerebral palsy and typically developing peers

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Introduction: Visual functions are poorly investigated in children with unilateral cerebral palsy (uCP) despite their importance for guiding motor actions in daily life. Hence, we investigated if visual acuity, stereopsis, visual-perceptual, and visuomotor functions differ between children with uCP and typically developing children (TDC), aged between 7 and 16.

Patients and Methods: Forty-eight children with uCP (mean age=11y10m±2y10m, 25 males, 23 right-sided uCP) and 49 age and sex-matched TDC (mean age=11y9m±2y11m) were recruited. Visual acuity was assessed using the Freiburg Vision Test ('FrACT'), stereopsis using the Titmus stereopsis circles subtest (TITMUS), visual-perceptual and visuomotor functions using five subtests of the Test of Visual Perceptual Skills (TVPS) and the Beery-Buktenica Developmental test of Visual-Motor Integration (Beery-VMI), respectively. Differences between groups were investigated using the Mann-Whitney U test and relative effect sizes (r).

Results: Compared to TDC, children with uCP scored significantly lower on the FrACT (p=.011, r=.26), the TITMUS (p=.004, r=.29), the subtests of the TVPS, namely visual discrimination (p<.001, r=.36), spatial relationships (p<.001, r=.45), form constancy (p<.001, r=.34), visual figure-ground (p<.001, r=.52), visual closure (p<.001, r=.55), and on the Beery-VMI subtests, namely visuomotor integration (p<.001, r=.55), visual perception (p<.001, r=.36), and motor coordination (p<.001, r=.50).

Conclusion: Children with uCP showed reduced visual acuity, stereopsis, visual perceptual, and visuomotor ability compared to TDC. These Results highlight the need for profiling the visual performance of children with uCP, which will allow the detection of specific visual deficits that might further compromise their level of functioning.

Relevance for users and families:

This work compares visual performance in children with uCP and TDC showing a significant decreased performance in children with uCP compared to TDC. However, despite the importance of vision in daily life, visual functions are still not enough investigated in clinical practice. Hence, these Results underline the necessity to include a comprehensive mapping of visual functions in the standard clinical care of children with uCP.

Oral Communication: Sport

Running characteristics of preschool age children born <30 weeks' gestation

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Introduction: Running is an essential part of children's function, but is not well understood in children born very preterm (VP; <32 weeks' gestation). This study aims to compare spatiotemporal running characteristics between children born VP and term, and its association with the risk for developmental coordination disorder (DCD).

Patients and Methods: A prospective cohort study of children born <30 weeks and term assessed at 4-5 years' corrected age. Cadence, step length, base-of-support, and single support assessed using GAITRite® during running. Oxygen saturation, heart rate, and Children's OMNI Scale of Perceived Exertion were assessed before and after running. DCD risk was identified as scoring ≤16th percentile on Movement Assessment Battery for Children-2, IQ >80 on Wechsler Preschool and Primary Scale of Intelligence, and without cerebral palsy.

Results: 112 term-born children and 111 children born VP (26 at risk for DCD). There was minimal evidence of differences in all running characteristics between children born VP and term. However, DCD risk was associated with shorter step length (mean difference[MD]= -4.62cm, 95%CI -7.14,-2.08) and shorter single support (MD= -2.81 seconds, 95% -4.71,-0.91) in children born VP. Further, children at risk for DCD showed a greater reduction in their oxygen saturation following running than children not at risk for DCD.

Conclusion: While children born VP run with comparable characteristics to their term-born peers, differences appear within the VP group. Specifically, children born VP at risk for DCD run with shorter steps and single support while showing greater oxygen saturation reduction than those not at risk.

Relevance for users and families:

Running is a crucial part of children's daily activities, sports, and play. This study helps develop our understanding of the impact of VP birth and the risk of DCD on children running. The DCD risk might indicate children needing targeted running screening and intervention. Further, the finding highlights the need for clinicians and early childhood educators to evaluate the running characteristics of preschool children born VP when planning interventions, sports, and school activities.

Effect of a community-based intervention (FitSkills) for young people with disability on physical activity participation: a stepped wedge cluster randomised trial

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Introduction: We determined if a community physical activity intervention (FitSkills) for young people with disability improved participation compared to usual activities.

Participants and Methods: A stepped wedge cluster randomised trial with 163 participants (13 to 30 years) and 11 gymnasia was completed. FitSkills matches a young person with disability with a mentor and the pair exercise together at their local gymnasium for 1 hour, two times per week for 12 weeks. Outcomes were collected on 8 occasions by blinded assessors. Participation attendance, involvement and preferences were measured using the Physical Activity Recall Questionnaire (PARQ), Sedentary Activity Questionnaire (SAQ), Children's Assessment of Participation and Enjoyment (CAPE), and Participation and Environment Measure for Children and Youth (PEM-CY) community module. Data were analysed using linear mixed effects models and Generalized Estimating Equations.

Results: PARQ data showed an increase in the time spent in physical activities (10%, 95% CI 0 to 19%) while CAPE (0.2 units, 95%CI 0.09 to 0.31) and PEM-CY (0.11 units, 95% CI 0.02 to 0.2) data showed a small increase in participation frequency compared to control period. There was a decrease in sedentary time (-456 mins/week, 95% CI -571 to -340), preference for physical activities (-8%, 95% CI -11 to -4) and desire to change (-7%, 95% CI -10 to -3) scores. There was no change in number of activities or participation involvement.

Conclusion: FitSkills increased the time young people with disability spent participating in physical activity, with corresponding decrease in sedentary activity, driven by an increase in participation frequency.

Relevance for users and families:

Young people with disability often have lower participation in physical activities than their peers without disability. Increasing physical activity participation in this group has the potential to have a positive impact on their physical, mental and social health. This large implementation trial shows taking part in a community physical activity program at the gym with a student mentor can increase the time young people with disability spend being active and reduce sedentary time.

The barriers and facilitators to physical activity in children with cerebral palsy: A scoping review

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Introduction: Lack of physical activity (PA) engagement and resulting low fitness levels are of concern for children with cerebral palsy (CwCP). This review aimed to establish barriers and facilitators to PA, as perceived by CwCP, parents and clinicians.

Methods: 'PubMed' and 'Web of Sciences' were searched by two independent reviewers. Qualitative articles in English published since 2001 describing barriers and facilitators to group PA were included. Both reviewers applied eligibility criteria and conducted assessment of methodological quality using the Mixed Methods Appraisal Tool (MMAT). Data obtained from the review was mapped out according to the 'International Classification of Functioning, Disability and Health – Children and Youth version' (ICF-CY) categories and the 'F-words' of childhood disability. Barriers and facilitators relating to each ICF-CY category/'F-word' were identified.

Results: Thirty-eight qualitative studies were included. Methodological quality was high; thirty-five of these studies met all quality items. Barriers relating to 'Environment/Family' were most frequently commented on throughout the literature, predominantly the lack of opportunities for PA and issues with accessibility/appropriateness of facilities. Similarly for facilitators, 'Environment/Family' and 'Participation/Friends' were most reported on. For the former, the key facilitator was family/parental support and encouragement, whilst for the latter this was PA as an opportunity to socialise and make new friendships. The single most frequent barrier was pain/fatigue, whilst for facilitators this was group PA as an opportunity to socialise/make friends.

Conclusion: Most barriers and facilitators identified were environmental/family related factors, hence, targeting this may have the highest potential to foster participation and create inclusive communities.

Relevance for users and families:

The identified barriers and facilitators to group physical activity (PA) in children with cerebral palsy (CwCP) inform behaviour change strategies, and planning of suitable activities to increase PA engagement and ultimately reduce risk factors of non-communicable diseases. This is particularly important for CwCP who already present with higher risk of these compared to typically developing peers.

Supporting young adults with disability to be active in the gym: Perspectives from the leisure and recreation industry

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Introduction: Social support is consistently reported as a key facilitator of community-based physical activity for young adults with disability, yet little is known about how it can be implemented by community gym facilities.

Patients and Methods: A qualitative study using an interpretive description approach was completed. Twenty-four gym and exercise professionals with diverse organisational roles (e.g. floor staff, gym operators) completed semi-structured interviews about known social support types and their organisational practices. Data were analysed deductively into social support types and then inductively to identify ways in which each type of social support was provided, and factors influencing implementation.

Results: Social support was implemented either as part of standard practice, or as part of a defined social support program.

Indirect supervision from gym staff, orientation to the gym and ongoing review of exercise programs were provided to all gym members irrespective of disability status. These strategies could be increased for those requiring additional support.

Defined social support programs combined multiple social support strategies in 1:1 or group settings to facilitate participation; most often exercise supervision, care support, specialist input, and extended orientation/familiarisation. These programs were usually driven by staff who were passionate about disability inclusion, by facilities with dedicated inclusion staff, or by local government councils who focused on disability inclusion as part of their strategic plan.

Conclusion: How social support is implemented in community gyms varies across facilities. Equity of access and inclusion in community gyms could be improved by scaling defined social support programs across the leisure sector.

Relevance for users and families:

This study provides an understanding from the gym and recreational industry perspective of how social support strategies are or could be implemented in gym settings to support young adults with disability. There is an opportunity for gym and leisure facilities to work with consumers, research partners, government and funding bodies to identify how to best implement social support within local contexts.

Pathways to participation: understanding the experiences of families of children with disability in gymnastics

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Introduction:The aim of this study was to understand the experiences of families of children with disability with participating in gymnastics, to inform how more supportive gymnastics environments can be created.

Patients and Methods:Sequential explanatory mixed-Methods study design. Eligible participants were parents or carers of children / young people with disability (any type, up to 25 years) who currently participate in, had participated in, or had attempted to participate in gymnastics in Victoria, Australia, in the last 3 years. Participants completed an online survey, with selected participants purposively invited to undertake a semi-structured interview. Sixty-eight parents provided survey responses, with eight interviews conducted. Quantitative survey data were analysed using descriptive statistics. Qualitative survey and interview data were analysed using inductive thematic analysis. All data were mixed to create a conceptual framework. Themes and the framework underwent member checking with parent advisors and interview participants.

Results:Five key themes emerged: 1) Tailored, accessible and supportive facilities and programs make a difference, 2) An explicitly inclusive club culture helps young people get involved and stay involved, 3) Coach knowledge about engaging children with disability is valued, 4) Enjoyment and recognition of achievement are key facilitators of ongoing participation and, 5) Gymnastics has physical and social benefits. The conceptual framework integrated themes into stages along the participation pathway.

Conclusion: Many participation-related interventions target children with disability and their families. Conversely, these findings provide guidance to gymnastics clubs on how to become more inclusive and supportive environments at each stage of participation.

Relevance for users and families:

Participation is the ultimate goal of timely intervention. The perspectives of parents about the pathways to, and experiences of, participating in gymnastics for young people with disability are essential in supporting gymnastics clubs become more inclusive and supportive environments. This means that timely intervention can extend beyond the clinic to community-based sport and leisure so that young people with disability have positive early experiences and the best chance of lifelong participation in physical activity.

Exploring the perceived facilitators and barriers to participation in rugby for children with disabilities: a mixed Methods study

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Introduction: Team sports, including rugby, are one of the most popular physical activities.However, young people in Ireland, particularly those with disabilities, are at risk of dropping out of team sports as they transition to adulthood. The development of inclusive sporting opportunities for people with disabilities is a key component of Irish sports policy. The aim of this study was to explore the facilitators and barriers to participation in rugby for youth with disabilities in Ireland.

Patients and Methods: A mixed Methods design was utilized. Ethical approval was obtained through the University of Galway, Ireland. The 'F-Words for Child Development' were used to design a holistic online questionnaire and interview protocol. Parents of children with disabilities that play rugby (n=39) and rugby club personnel (n=47) were invited from the 200 clubs identified with a youth team to take part in the survey. Semi-structured interviews were conducted with three youths with disabilities from a mixed ability rugby club. Thematic and statistical analysis were conducted.

Results: Parent themes were 1) 'Striking the Right Balance' and 2) providing a 'Variety of Options to Match the Variety of Values'. Club personnel themes were 'Opportunities and Challenges of' 1) 'Inclusion' and 2) 'Development'. The youth players described rugby as an important and meaningful activity.

Conclusion: This study was the first to examine the facilitators and barriers affecting rugby participation for youth with disabilities in Ireland. Each 'F-Word' demonstrated relevance to rugby participation, indicating the potential usefulness of the framework in guiding participation development opportunities.

Relevance for users and families:

Relevance for users and families: Participation in team sports is associated with numerous physical and mental health benefits, both for the players involved and for their families. These benefits can be highlighted and described using the 'F-Words in Child Development' framework. The use of the 'F-Words' to develop rugby participation opportunities may enable more players and their families to experience these benefits.

Oral Communication: Hand Function

Feasibility and impact of an early bimanual stimulation home-program on quality and quantity of upper limb movements in infants at risk of unilateral cerebral palsy

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Introduction: To explore the feasibility of BB-Bim, a new home-based early intensive bimanual stimulation program, and its impact on quality and quantity of upper limb movements in infants at risk of unilateral CP.

Patients and Methods: N-1 trial, multiple baseline design across subjects, baseline randomized from 4 to 7 weeks, followed by 8-week-intervention comprising parent-provided bimanual stimulation 20 min/day, 6 times/week, with one weekly occupational therapist coaching visit. Infants had to present a unilateral brain lesion and under-use of the upper limb at inclusion. Feasibility and relevance were assessed through a logbook and a parental report including ten continuous 0-10 scaled questions. BB-Bim impact was assessed trough weekly repeated measures: Hand Assessment in Infants (HAI), Goal Attainment Scales (GAS), and accelerometry parameters collected during HAI and spontaneous activity periods using two AX3 Axivity monitors in wrist-worn bracelets.

Results: 6 infants (3-11 months) were included. Parents provided meanly 3,4 to 6,2 stimulation sessions/week. They reported high feasibility, relevant intensity, length and therapeutic support. They appreciated their active role, felt competent and reported BB-Bim efficiency.

Stimulation significantly improved HAI bimanual items and total score for all infants, without significant impact on unilateral scores. GAS scores increase was significant for 3 infants.

Actimetry was analyzed during HAI and 238 spontaneous activity sessions (mean 42±21 minutes). Actimetry ratios distribution and evolution showed a high variability, especially for spontaneous activity, without significant trend.

Conclusions: BB-Bim proved its feasibility and tends to improve bimanual function in infants at risk of unilateral CP.

Relevance for users and families:

Home-programs where parents take an active part in their infant stimulation, coached by a therapist once a week, are feasible and look relevant and efficient to families.

Bimanual stimulation seems to improve bimanual interactions in infants at risk of unilateral CP, as measured by HAI and GAS.

Despite its feasibility, using accelerometry bracelets looks unreliable for detecting and monitoring hand function in infants under one year.

Therapist fidelity in a multi-site randomized comparative efficacy trial of Baby-CIMT and Baby-BIM for infants with unilateral cerebral palsy

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Introduction: Interventions to improve hand function for infants with unilateral cerebral palsy (UCP) are complex. Measuring fidelity, the extent that therapists deliver interventions, is critical to attribute outcomes to key intervention components. The Rehabilitation EArly for Congenital Hemiplegia (REACH) study is a randomized trial comparing equal doses of constraint-induced movement therapy (Baby-CIMT) and bimanual therapy (Baby-BIM). Purposes of this sub-study were to quantify fidelity of therapist delivery and determine factors impacting fidelity.

Patients and Methods: N=96 infants at high risk of UCP, aged 3-9 months, were randomized to Baby-CIMT or Baby-BIM. Therapists completed standardized training for delivering interventions using parent coaching. Bi-monthly intervention sessions were video-recorded and scored using an intervention-specific fidelity checklist (TFC). The first session and a random sample of 10% of subsequent sessions were scored (n=72 sessions). A-priori thresholds were ≥80% (TFC score ≥13/16) for high and 50%-<80% (TFC score 8-12/16) for moderate fidelity. Spearman's rho was calculated for TFC scores and infant age, Hand Assessment for Infants, and Pediatric Rehabilitation Intervention Measure of Engagement-General.

Results: Fidelity was high for 88.9% and moderate for 11.1% of sessions. Sessions with moderate scores included infants receiving Baby-BIM and occurred at intervention midpoint or later when manual development becomes more lateralized for infants with UCP. No significant relationships were found for TFC scores and age (p=0.054), manual ability (p=0.205), or parent engagement (p=0.377).

Conclusions: Fidelity was high for the REACH trial in most intervention sessions. Standardized therapist training with intervention manuals and monthly peer-to-peer support contributed to these positive Results.

Relevance for users and families:

Consistency among therapists in delivering intervention (fidelity of delivery) is important for achieving best outcomes for individuals with CP. Measuring fidelity of delivery helps link intervention components to outcomes. Standardized therapist training, intervention manuals, and therapist peer-to-peer support throughout an intervention period can result in high fidelity of delivery for complex interventions, such as Baby-CIMT and Baby-BIM.

Effect of Interactive web-based Constraint induced movement therapy for infants (iBaby-CIMT) below one year

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Introduction: Constraint-induced movement therapy (CIMT) has been developed for different age groups and recently for infants. Earlier CIMT models provides intensive training face-to-face by home visits or in the clinic. The study aim was to investigate whether an internet-based program with interactive web meetings (iBaby-CIMT) is as effective as Baby-CIMT by home-visits.

Patients and Methods: 18 iBaby-CIMT children, age 4-8 months with high risk of unilateral CP are compared to 18 historical controls, included in a previous intervention RCT study (Eliasson et al 2018). Both studies used the same protocol regarding inclusion criteria, data collection as well as the amount of training. The training lasted for two periods of 6 weeks each (30 minutes daily) with a 6 weeks break in between.

The iBaby-CIMT program included interactive web meetings where the child and parent met the therapist once a week carrying out a training session remotely. Diaries were kept and noted on the web platform, which also provided the family with informative material. The primary outcome for comparison of the two groups was hand function measured by Hand Assessment for Infants (HAI).

Results: Preliminary Results indicate that children with iBaby-CIMT as intervention present the same positive result as those with Baby-CIMT through home-visits. Data analysis are ongoing.

Preliminary Conclusion: iBaby-CIMT seems to be as good as Baby-CIMT with home visits.

Relevance for users and families:

Relevance for users and families: This result indicate that the interactive internet-based model is as well received as the previous home based model. Since e-health develops quickly with the advantage of providing equal patient-centered healthcare interventions remotely, we think that this method will be cheaper enhancing availability for more children.

Fidelity of Hippotherapy and Physical Therapy in the Equine Environment to Target Upper Extremity Function and Participation in Children with Cerebral Palsy and Autism Spectrum Disorder

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Introduction: Cerebral palsy (CP) and autism spectrum disorder (ASD) can include impaired upper extremity (UE) function. This can decrease participation, a major goal of therapy for many children and families. Hippotherapy and physical therapy in the equine environment (PTEE) might target UE function and participation. This study aimed to evaluate the fidelity of hippotherapy and PTEE to provide a high dose of UE and participation-based treatment for children with CP and ASD.

Patients and Methods: 11 children ages 6-13 with CP and/or ASD received 16 hours of therapy over 4 weeks. Each 1-hour session included PTEE and at least 15-minutes of hippotherapy. Fidelity was evaluated using Datavyu to code the duration of time spent on UE and participation-based activities from video recordings of the treatment sessions.

Results: UE activities comprised 65-78% (mean 73%) of the total session; 69-88% (mean 78%) of hippotherapy; and 55-79% (mean 71%) of PTEE. Participation activities comprised 61-87% (mean 77%) of treatment activities during the entire session; 36-87% (mean 55%) of hippotherapy; and 81-94% (mean 88%) of PTEE. UE use was greater in the treatment blocks later in the study (block 3: 78%, block 4: 79%), compared to the blocks delivered earlier in the study (block 1: 65%; block 2: 73%).

Conclusion: The intervention delivered a high dose (>50%) of UE and participation-based activities, more so with PTEE than hippotherapy. This intervention shows promise in targeting patient and family goals of increased participation. Next, a Phase II trial should evaluate preliminary efficacy of the intervention.

Relevance for users and families:

Hippotherapy and physical therapy in the equine environment (PTEE) can be engaging and fun for patients. Hippotherapy is effective in improving gait and balance in children with cerebral palsy, and adaptive behaviors and gross motor function in children with autism spectrum disorder. This study begins to address whether hippotherapy and PTEE might be applied to improve upper extremity function and participation, which could expand the application of hippotherapy and PTEE to a variety of populations.

Trunk and upper extremity kinematics measured by markerless motion tracking in individuals with and without dyskinetic cerebral palsy

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Introduction: Three-dimensional motion capture (3D-MoCap) is the gold standard in movement analysis. However, 3D-MoCap is expensive and markers need to be attached to the skin. Markerless motion tracking (MMT) from common videos is fast evolving and potentially valuable for movement analysis in childhood.

In this proof-of-concept study, we assessed feasibilty and validity of MMT for trunk and upper extremity analysis in individuals with dyskinetic cerebral palsy (DCP).

Methods: A reaching-sideways-task was performed ten times measured by 3D-MoCap and frontally filmed with a common video camera. Anatomical landmarks of the trunk and upper extremity were tracked using open-source software DeepLabCut. Trunk lateroflexion, shoulder elevation, elbow and wrist flexion/extension were calculated at point of task achievement using both MMT and 3D-MoCap. MMT and 3D-MoCap variables were relatedusing Pearson correlation coefficient and compared between DCP and typically developing (TD) peers using independent T-tests.

Results: 30 Participants (15 DCP: age:17.6±4.7y, MACS level:I(n=2), II(n=7), III(n=6) ; 15 TD: age:16.7±4.6y) were included. Shoulder elevation and elbow flexion/extension from MMT correlated to 3D-MoCap angles ($r=0.58$-0.63;$p<0.01$), while wrist flexion/extension and trunk lateroflexion did not show a significant correlation ($r=0.33$-0.36;$p>0.05$).Less elbow extension ($p=0.01$, mean difference 9^{o}[CI 1.9-15.9^{o}]) and more lateroflexion towards the target ($p=0.01$, mean difference 3^{o}[CI 0.9-5.8^{o}]) were found for the DCP group in comparison with TD individuals. Shoulder elevation and wrist/flexion extension did not significantly differ between groups.

Conclusion: Shoulder and elbow variables can be validly measured with MMT within a reaching task, while wrist and trunk variable were less valid possibly related to projection errors.

Relevance for users and families:

The proposed method is promising for movement analysis in DCP. As an assessment tool using only videos, this method may allow frequent measurements of upper extremity and trunk movements in a natural environment such as at home or school. Such frequent measurements can support clinicans in the indication, monitoring and fine-tuning of treatment management in individuals within DCP and thereby help to proceed towards a more individualized approach.

Understanding Autism and Its Treatment: A Child's Point of View

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Introduction: Including the child's perspective within health care settings is important for their emotional development and for optimal outcomes. While perceptions of parents and professionals regarding children with ASD have been studied extensively, limited data is available regarding the child with Autism Spectrum Disorder (ASD)' point of view.

Aim: To examine the perception of children with ASD about their condition and their participation in treatment processes.

Methods: Ten children and adolescents (age 7-13 years) formally diagnosed with ASD (Average DQ =86.80, SD=13.41) were interviewed in person in a clinical setting. A qualitative approach was used, focusing on the children' perceptions of their (1) strengths and challenges; (2) understanding of a proposed ASD novel treatment and their willingness to participate. The interview included both direct and projective open-ended questions for each topic. Children's answers were analyzed using interpretative content analysis.

Results: Children shared their emotional and behavioral challenges in the familial and/or educational contexts and discussed "normality" vs. "disability" themes. Children varied in their awareness regarding their diagnosis/symptoms. Only one boy named his diagnosis and described it's consequences in detail. Most children were not aware of the therapeutic aim of the upcoming intervention, however showed interest in receiving this information from their parents and/or professionals.

Conclusions: Children with ASD are aware of their unique emotional and behavioral challenges yet are frequently excluded from the informing process. Results shed light on the need to explore developmentally and emotionally adaptive ways to involve children when discussing their neurodevelopmental diagnosis and possible interventions.

Relevance for users and families:

Results display the perception of children with ASD regarding their condition and their participation in treatment processes. Results shed light on the need toexplore developmentally and emotionally adaptive ways to involve children when discussing their diagnosis andinterventions.

Oral Communication: Goal Setting 2

The effect of community-based participation and environmental factors on physical activity levels for preschool age children born <30 weeks' gestation and at term

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Introduction: Pre-school age children born very preterm (VP: <32 weeks' gestation) are less physically active than term-born children. Interventions to improve physical activity (PA) frequently focus on increasing community participation through addressing environmental barriers. However, the impact of these barriers on PA for children born VP is unknown.

Patients and Methods: Longitudinal study of children born <30 weeks (n=39) and at term (n=84), recruited from the Royal Women's Hospital, Melbourne Australia. Community participation, including perceived environmental supports and resources, were assessed at 4-5 years' corrected age using the Young Children's Participation and Environmental Measure (YC-PEM). PA was measured using a tri-axial accelerometer. Regression models were used to estimate the effect of community participation on the average increase in minutes per day of PA (β), and to assess whether this effect varied between birth groups.

Results: Children who participated more frequently in community activities were more physically active, but evidence was not strong (β = 13.2, 95% confidence interval [CI]; -20.2, 46.6). There was little evidence to suggest higher involvement in community activities increased mean PA (β = 1.5, 95%CI; -31.1, 28.1). Better environmental supports and resources were associated with more PA (β = 3.0, 95%CI; 0.9, 5.1). There was little evidence to suggest that the effect of community participation varied between children born VP and term.

Conclusion: At preschool age, better environmental supports and resources, such as availability of programs, funding, and attitudes of others, were associated with higher PA levels.

Relevance for users and families:

Physical activity participation at preschool age is important for developing motor, cognitive and social skills, and physical fitness. Environmental factors, such as the difficulty of motor activities or sensory qualities of activities, may be appropriate intervention targets for families and clinicians to promote physical activity at preschool age. Policy makers should consider the impact of environmental resources on physical activity participation, given the effect of physical activity behaviours on long term health outcomes.

Strategies of therapists to promote motor engagement in pediatric rehabilitation: a qualitative study

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Introduction: The challenge of pediatric rehabilitation, especially in chronic conditions, is to obtain optimal motor engagement to improve motor learning. Different theoretical models have been reported in the literature. The aim of this study was first to create a combined model of strategies of engagement for children with motor disabilities and to compare it to the real practice of therapists.

Method: A review in the field of care and education was carried out and a synthesis led to a new model of engagement strategies adapted for children with motor disorders. Thus semi-directed interviews were conducted with physical and occupational therapists to find out what strategies they spontaneously use in their practices. The verbatim was systematically classified according to the model.

Results: A review of the literature identified 5 main areas with a total of 18 strategies reported to promote motor engagement of children as a mind map. 8 therapists, representing the diversity of practices and profiles led to a saturation of the verbatim. All the strategies (18/18, e.g. “goal-directed” or “family-centered” approach) of the theoretical framework were cited and additional strategies (+2, e.g. the “child should decide by himself its activities”) were added by the therapists interviewed. At the individual level, 42 % to 66% of the strategies were used meaning that no therapist was using all the strategies described in the theoretical framework.

Conclusion: Targeted training is needed to disseminate all strategies of engagement in motor pediatric rehabilitation. The produced mind map can be a good support for dissemination.

Relevance for users and families:

Children's engagement during the rehabilitation program is essential and necessary to optimize the time devoted to it. These Results highlight the central role of children during their rehabilitation program and will help children and their families to spend more time on family and individual occupations.

Physical capacity and physical activity in children with Heritable Connective Tissue Disorders (HCTD)

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Background: Health problems in children with heritable connective tissue disorders (HCTD) are diverse and complex and might lead to lower physical activity and physical functioning. However, it is unknown if and to what extent physical capacity (PC) and physical activity (PA) are affected in children with HCTD.

Methods: This cross-sectional, multicenter study included 56 children (median (IQR) age: 11.6 (8.8-15.8) years; 59% male), with molecularly confirmed EDS (n=13), Marfan syndrome (MFS) (n=40) and Loeys-Dietz syndrome (LDS) (n=7) and approval from the pediatric cardiologist. PC was measured as 1) cardiovascular endurance; Fitkids Treadmill Test (FTT), 2) muscle strength; hand grip dynamometry (HGD), and 3) motor proficiency; Bruininsk-Oseretsky Test of Motor Proficiency-2 (BOT-2). PA was assessed by the 1) Paediatric Evaluation of Disability Inventory Computer Adaptive Test (PEDI-CAT) subscale mobility, and 2) accelerometer-based activity monitor (ActivPAL). Results are shown as mean (SD) Z-scores for PC and mean (SD) for PA.

Results: Regarding PC, children with HCTD scored severely reduced on the FTT (-3.3;3.2), and mild reduced on the HGD (-.24;1.0) Compared to normative data. The scores on the BOT-2 were comparable to normative data (-.24;1.0). Regarding PA, HCTD children were active for 4.4(1.1) hours and inactive for 8.8(1.7) hours/day and performed 8595.9(3565.1) steps a day.

Conclusion: This study is the first to demonstrate severely reduced PC and PA in children with HCTD. A possible explanation for reduced cardiovascular endurance and muscle strength is deconditioning in combination with genetic factors. This study provides a starting point for tailor-made interventions.

Relevance for users and families:

This study provides a starting point for tailor-made interventions to improve Physical activity and physical fitness in children with HCTD. It also provides a core set of measurement tools that can be used by clinicians or paramedics to measure or objectify PC and PA in children with HCTD.

Goal Attainment Scaling in paediatric rehabilitation: a comprehensive literature-based didactical tool box for implementing GAS

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Goal Attainment Scaling (GAS) is a person-centred and collaborative approach, allowing to assess the effectiveness of an intervention on personally relevant goals. However, GAS is not a "scale" but a heterogeneous group of methodologies, including many variations and lack of consensus on high quality GAS. Consequently, clinicians and researchers may implement lower quality GAS variants and may not be aware of how inadequate GAS quality influences Results of patients and clinical trials using it as an outcome measure.

The aim of this special communication is to: (1) provide updated didactical information and tools on GAS use in rehabilitation practice and research; (2) increase awareness of GAS methodological challenges; (3) guide use of GAS as an integrated process of rehabilitation after goal setting.

This communication is based on a literature review to provide a synthesis of current GAS applications relevant to rehabilitation fields. Practical advice is provided regarding clinical challenges in GAS: definition of 0 level, types of relevant goals, time-frame and means employed to attain the goal, dealing with unforeseen pattern of improvement. Challenges with GAS in rehabilitation research are also presented in order to promote researcher's awareness on reliable use of GAS and encouraging best-use of GAS.

Relevance for users and families:

Therapists' awareness will be increased in order to be more capable to build relevant Goal Attainment Scales with their clients. The effectiveness of therapeutic interventions could thus be measured with tools that make sense for the clients, linked to their significant activities and participation.

Relevance of Goal Attainment Scales in Home Treatment of children with neurodevelopmental disorders

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Objective: Children with neurodevelopmental disorders often show problem behaviours, which can lead to significant parental stress and may affect the quality of life of all family members. Our Home Treatment programme offers behavioural therapy with individualised parent training. A positive effect on child behaviour, parenting stress and parent-child-interaction has previously been shown. Additionally, the achievement of individually set treatment goals was analysed.

Patients and Methods: As part of the Home Treatment study 56 families received home based therapy for on average 13,81 (SD 4,74) weeks with targeted behavioural interventions, video analyses and psychoeducation. Besides standardized questionnaires and video analyses, individual treatment goals were defined together with the caregivers prior to the intervention focusing on the most challenging behaviour of each child. Goal Attainment Scales (GAS) (Kiresuk & Sherman, 1968) were used to measure individual therapeutic outcomes.

Results: The goals were assigned to seven focus areas in posterior analyses: (auto-)aggressive behaviour (N=14), eating (N=23), cooperation (N=33), personal hygiene routines (N=14), toilet training (N=9), sleep problems (N=12) and "others" (N=26). On average 2,34 (SD 0,769) goals per child were set. The median change in GAS was 2,00 ($p<.001$). GAS-Scores after therapy did not correlate with change scores in standardized questionnaires.

Conclusion: GAS revealed a significant change in individual challenging behaviour. Standardized questionnaires seem to measure other outcomes than GAS, which confirms the clinical opinion of the therapists. Especially in children with neurodevelopmental disorders and multiple problems GAS may help to focus on the most important goals for the child and its parents.

Relevance for users and families:

Children with neurodevelopmental disorders (NDD) often display problem behaviour. Although standardized questionnaires especially for children with NDD are available, they may fail to measure what's most challenging in everyday life. Thus, an individualized goal setting and outcome measurement in behavioural interventions is needed. Goal Attainment Scales are a useful tool to plan and evaluate child and family centered therapy. They show significant therapy effects in line with standardized questionnaires.

Telerehabilitation of infants at risk of Cerebral Palsy during the COVID-19 pandemic: effectiveness on the goals of the caregivers

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Introduction:An alternative mode of therapy during the COVID-9 pandemic was telerehabilitation. We aimed to verify the impact of a telerehabilitation program on the goals of the caregivers and their satisfaction.

Patients and Methods:A pre-post feasibility study, approved by the local ethical committee (UFSC-CAAE:33771120.0.0000.0121). Ten caregivers and infants at risk of cerebral palsy were included. Telerehabilitation was applied by caregivers at home, five times a week, for 12 weeks. The program included guidance for optimal positioning, optimization of goal-directed activities, environmental enrichment, and educational strategies. The Goal Attainment Scaling (GAS) T-score was applied before and after telerehabilitation. The Wilcoxon test was applied to compare the GAS T-score ($p \leq 5\%$). We also applied a questionnaire about the caregiver satisfaction at the end of the telerehabilitation program.

Results: We found a significant improvement equal to 33.5 of the T score of the GAS at the end (median=30.5; minimum=24.8; maximum=35.1) compared with the goals established before (median=64.0; minimum=56.9; maximum=74.9) the telerehabilitation program ($Z=-2.805$; $p=0.005$). Caregivers reported facility to apply the program at home (7) and to adapt the program to their daily routine (7), and satisfaction with the program (10). All caregivers would recommend the telerehabilitation to other families, felt empowered by the program, and actively participated in the definition of the goals of the telerehabilitation program. In addition, all caregivers considered that the infant motor behavior and mother-infant interaction improved.

Conclusion:Telerehabilitation during the COVID-19 pandemic improved the goals defined by caregivers.

Relevance for users and families:

Telehealth could also be a feasible alternative rehabilitation for some populations that do not have access to health services due to financial and geographical issues.

Oral Communication: Movement

Mitochondrial energetics in impaired muscle growth and across functional levels in children with cerebral palsy

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Introduction: Children with CP have impaired muscle growth, develop contractures and reduced ability to move. Muscle mitochondria primarily produce energy needed for muscle contraction. Mitochondrial energetics increase during growth and are reduced with muscle disuse. Here we assessed mitochondrial energetics between contractured and non-contractured muscles, to assess growth impairments and in ambulatory and non-ambulatory children with CP, to assess disuse.

Patients and Methods: Thirty-two children with CP (11.4 ± 0.6 years, 21 male, 12 female, 16 ambulatory, 16 non-ambulatory) from whom forty-three muscle biopsies were obtained from non-contractured muscle (vastus lateralis), or contractured muscles (adductors and gastrocnemius) during surgery. Carbohydrate/fatty acid protocols on permeabilized muscle fibers for mitochondrial energetics, citrate synthase assays for content and muscle cross-sectional areas for myofiber size were measured.

Results: Contractured adductor muscles, but not gastrocnemius had a significantly lower maximal mitochondrial energy production capacity than non-contractured muscle (73 ± 6, 96 ± 7, 102 ± 6 pmolO2/s/mg, respectively, $p<0.05$). Neither fiber type-1 percentage nor average myofiber cross-sectional area in contractured muscles were associated with maximal mitochondrial energetics. Mitochondrial capacity was not explained by mitochondrial content and mitochondria preferential used carbohydrates over fatty acids. Surprisingly, mitochondrial energetics contractured muscles in independently ambulatory children were similar to that in non-ambulatory children (88 ± 8, 84 ± 9 pmolO2/s/mg).

Conclusion: Skeletal muscle mitochondria in contractures are altered that appears to be different from disuse atrophy. Fiber type proportions do not reflect muscle mitochondrial oxidative capacity. Altered mitochondrial physiology may be responsible for impaired muscle growth leading to contractures.

Relevance for users and families:

Muscle mitochondria are responsible for energy production. This energy is used during muscle contraction during movement. Muscle growth is reduced in some muscles leading to contractors, while some children walk independently while others need wheelchairs. With disuse mitochondria reduce energy capacity, while it increases during muscle growth. Here we assess if mitochondria in muscle contractures are similar to non-contractured muscles. Additionally, we see if mitochondrial function is different between independently ambulatory and wheelchair dependent children.

Muscle strength, muscle volume and functional mobility in children with spastic cerebral palsy

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Introduction: Muscle volume, strength, and functional mobility in children with cerebral palsy (CP) are complexly interrelated, which we aimed to elucidate, and compare to typically developing (TD) children.

Patients and Methods: 14 children (6 girls) (median age; 8,6 years) with spastic CP (unilateral:6, bilateral:8) GMFCS-level I:11, II:3, naïve to botulinum toxin and 14 TD children (8 Girls) (9,4 years) participated. Measurements were maximal isometric strength with a rig-fixed dynamometer in plantarflexors (PF), and dorsiflexors (DF), muscle volume using MRI in gastrocnemius, soleus, and tibialis anterior, in the more- (MAL) and less affected (LAL) leg in children with CP and solely right side for TD children, functional mobility with the Timed Up and Go test (TUG) in children with CP. Nonparametric statistics were used.

Results: Muscle strength (Nm/Kg) in PF in TD children and children with CP did not differ ($p>0.05$). DF strength was higher in the TD-group compared to MAL in the CP-group (0.55 [0.43-0.70] ;(0.15 [0.00-0.52], $p<0,001$). In the CP-group, LAL compared to MAL was stronger in both PF ($p=0.041$) and DF ($p=0.023$). The BSCP-group was stronger in LAL in the PF ($p=0.012$). Muscle volume (cm^3) did not differ between the groups, or between LAL or MAL in the spastic group. No correlations between TUG, strength or muscle volume were found.

Conclusions: Muscle volume, strength, and functional mobility did not correlate in children with CP functioning at GMFCS levels I and II. Surprisingly, muscle volume did not differ compared to TD, despite weaker DF in the children with CP

Relevance for users and families:

In this group of children with CP walking without support muscle volume, strength and mobility were not related. Despite weaker ankle dorsiflexor muscle in the children with CP muscle volume did not differ, but an asymmetrically strength difference could be seen where the less affected leg were stronger. What factors contribute to functional mobility and muscle strength in children with CP need to be further explored and may contribute to optimized treatment.

The impact of ankle foot orthoses on functional gait parameters and energy efficiency in children with cerebral palsy.

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Introduction: Ankle-foot orthoses (AFO) are prescribed for ambulatory children with cerebral palsy (CP) to reduce gait abnormalities and related limitations in physical mobility[1]. The impact of AFOs on energy efficiency is unclear[2]. Total Heart Beat Index (THBI) is a reliable & valid measure of walking efficiency[3].This study aims to determine the impact of AFOs on functional gait parameters and energy expenditure in children with CP using the THBI.

Methods: A repeated-measures study using the 6-Minute Walk Test (6MWT) to evaluate differences in heart rate, walking speed, distance, rate of perceived exertion (RPE) and THBI was conducted in independently ambulating children with CP (n = 21; age 5-16 years). Children performed two tests, with and without AFOs, while wearing a heart rate monitor, with a 10-minute rest in between. Differences in parameters between groups were compared using a paired-t-test, and within group differences using a repeated measures ANOVA ($p<0.05$).

Results: There was no significant difference in distance (AFO & Shoes:427m, Shoes only: 408m p=0.27), walking speed (AFO & Shoes: 1.19m/s, shoes only: 1.13 m/s p=0.27), Heart rate (AFO & Shoes: 718bpm, Shoes only: 722bpm, p=0.92) or THBI (AFO & Shoes: 1.72; Shoes only: 1.82, p=0.47) between tests. Significant differences in THBI were observed in the minute-to-minute variability for the AFO and shoes group.

Conclusion: This study demonstrates that use of AFOs does not negatively impact walking efficiency which is important in their prescription and compliance.

References

(1) Morris et al 2002

(2) Brehm et al 2008

(3) Kimoto et al 2002

Relevance for users and families:

The Results of this study are important in reassuring families that AFO use does not increase the energy cost of walking. Therefore this may increase the child and family's confidence and compliance in the daily use of AFOs.

Use of the Quality Function Measure (QFM) to evaluate change in the quality of movement in ambulant children with cerebral palsy following lower limb Botulinum Toxin-A (BoNT-A) injections

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Quality of movement (QoM) is an essential component of motor skills in children and young people with Cerebral Palsy (CYPwCP), influencing their level of activity and participation opportunities. BoNT-Ais used to reduce dynamic spasticity to optimize children's functional skills, however there is little direct evidence that movement quality improves.This prospective study evaluated change in QoM in ambulatory CYPwCP using the QFM over a 12-month period following lower limb BoNT-A treatment

Methods: 64 ambulant CYPwCP participated in the study (mean age at injection 7y 5mo (SD 2y 8mo)).The QFM was administered following a standardized protocol using dimensions D & E of the Gross Motor Function Measure. Change from baseline was evaluated for all QFM attributes at 6-weeks, 6-months and 12-months post injection.

Results:One-way repeated measures ANOVA showed significant improvement in all QFM attributes from baseline across 12 months following BoNT-A ($p<.001$), with high correlation between all attributes at each time point ($r = 0.88$-0.98, $p<.001$). However, the timing of a clinically significant improvement differed between the different attributes.Alignment improved from 6-weeks whereas significant changes in Co-ordination, Dissociated-Movement, and Weight-shift took longer, reaching clinical significance by 6-months.All attributes were maintained for 12-months.

Conclusion: These Outline suggest that BoNT-A within a treatment programme can be associated with improvement in QoM in CYPwCP.The variation in onset of improvements in the different QFM attributes has implications for clinical practice, suggesting that rehabilitation should continue beyond the immediate post injection period, to potentiatethe effects and reducere-injection frequency.

Relevance for users and families:

Traditionally children and families engage in intensive blocks of rehabilitation after botulinum toxin treatment, between 6-and12-weeks post injection.This often includes home and school programmes and an increase in physical activity. This study suggests an activity programme for longer has potential for continued improvement in quality of movement, extending the benefits of BoNT-A.Focus on physical activities that a child enjoys, would make this more acceptable as would the likely reduced frequency of re-injection.

Kinematic Trajectories Throughout Childhood in Cerebral Palsy: The Influence of Age and Orthopedic Surgery

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Introduction:The purpose of this study was to analyze changes in gait throughout childhood in children with cerebral palsy (CP) to determine the influence of age and orthopedic surger(ies) on kinematic outcomes.

Patients and Methods: IRB approved prospective cohort. Children with spastic CP (GMFCS I-III) were recruited between ages 17 to 40 months. Instrumented gait analyses (IGA) were performed serially over ages 6 to 21 years to collect kinematic data at self-selected, bare-foot walking speed. The primary outcome measure was the change in Gait Profile Score (ΔGPS). ΔGPS was analyzed by age distribution (<10, 10-15, ≥15 years) and by presence/absence of surgery.

Results: 31 children were included [diplegic(16), hemiplegic(15); GMFCS: I(13), II(14), III(4)]. Children completed 5.8±1.6 IGAs, 2.5±1.3 years apart. Comparing the ΔGPS between the initial (at 5.8±1.1 years) and final IGA (at 17.8±2.1 years) 86% of the limbs were improved or unchanged. 180 total (person) visits provided 298 intervals of ΔGPS (per limb) that were classified as nonsurgical(n=235) or surgical(n=63). More GPS improvement was identified in intervals with surgery (-1.4±2.9) compared to without surgery (0.1±2.4; p=0.0004).By age interval, significantly more GPS improvement was identified in the <10-year-olds versus the 10-15/≥15-year-old groups; regardless of whether surgery had been performed (p<0.014).

Conclusion:Trajectories of gait function in children with CP are greatly influenced by age and surgical intervention. Improvements in gait are more likely in early in childhood.Orthopedic surgery had a positive impact at all three age groups, with the greatest changes seen in children under age 10.

Relevance for users and families:

Information gleaned regarding the positive role of orthopedic surgery on gait may be imparted during parent/patient pre-operative counseling to help in decision-making.

A retrospective cohort study about the hip luxation in non-ambulatory cerebral palsy patients: the point of no return

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Introduction: The migration percentage (MP) is a widely used criterion for surgery in displaced hips. Literature suggests that no hip can spontaneously improve if the MP exceeds 45%, in a mixed population of cerebral palsy (CP) children. The aim of the present paper was to identify the point of no return of the MP in a selected sample of non-ambulatory CP children, being the most exposed to hip luxation.

Patients and Methods: This single-centre retrospective cohort study included patients with spastic or dyskinetic CP, GMFCS level IV or V, age 0-18, having at least three pelvic radiographies, excluding radiographies relative to hips having previously undergone surgery. The following information was collected: sex, CP subtype, GMFCS level, drug-resistant epilepsy, MP, age at assessment, use of walking or standing assistive devices standing tables or weight support walkers, previous botulinum injection, oral or intrathecal baclofen, hip pain. Data were analysed at the level of the individual hips. Descriptive statistics were presented. Receiver operating characteristic (ROC) curve analysis was conducted to investigate which value of the MP could be adopted as the "point of no return": i.e., the cut-off value beyond which no MP reduction, by more than 5%, could be expected.

Results:The optimal cut-off value was identified as MP≥ 50%, with a sensitivity of 84.5% and a specificity of 100% (p-value <0.001).

Conclusion: MP≥ 50% is the "point of no return" for GMFCS IV-V CP patients, representing the cut-off value beyond which no spontaneous MP reduction may be expected, unless addressing surgery.

Relevance for users and families:

MP ≥50% represents the cutoff value for non-ambulatory CP subjects, beyond which no MP reduction could be expected by means of conservative approaches. Then the professional and the family should ponder risks and benefits, in particular for the frailest subjects, and decide to face surgery or the likelihood of increasing hip displacement.

Oral Communication: Goal Setting 1

"Shall we start? Ready, Set, Go! Towards early intervention in infants with unilateral cerebral palsy. preliminary Results

Rocío Palomo[1], Elena Pinero-Pinto[2], Cristina Lirio-Romero[1], Helena Romay-Barrero[1], Asunción Ferri-Morales[1], Rita-Pilar Romero-Galisteo[3]

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Introduction: The great plasticity of the brain during the first 2 years of life primarily indicates the importance to begin training at an early age. Objetive: To evaluate the feasibility of different intensive therapies (infant-CIMT, infant-BIT or infant-hybrid) at home with the family involvement directed to the children with unilateral cerebral palsy from 9-18 months.

Patients and Methods: Children were randomized into four groups: infant-mCIMT (n=10), InfantBIT (n=10=, Infant-hybrid (n=10) and Infant-standard-Therapy (n=10, control group, CG). Each early intensive protocol lasted 50 h and was applied throughout a 10-week period with the family involvement at home. The main outcome was the feasibility of intensive therapies at home and the effectiveness related to bimanual functional performance, measured with mini-Assisting Hand Assessment scale (mini-AHA), Functional Goals measured with Goal Attainment Scale (GAS) and Satisfaction-expectations on intensive therapy from parents measured through a specific questionnaire. Three measures were performed (week0, week10 and 6-months).

Results: Forty infants aged 12.38 months (SD:2.92) met the inclusion criteria for enrollment in the therapy programs. All groups showed a great adherence in the intensive programme (>90% of dose). And significant increasements were obtained after intensive therapies in the BFP and at 6-month compared to baseline-assessment ($p<0.01$), except for control group in 6-month ($p=0.81$). Satisfaction was higher for the Infant-BIT group reaching a score of 2/5 ($p<0.01$).

Conclusion: Early intensive therapies can be applied at home with the family involvement andallow to obtain more increases in the BFP and maintained at 6-month follow-up compared with the Infant-standard therapy.

Relevance for users and families:

know how to interact with their children within the natural environment, receiving continuous support and feedback from the therapist that will foster their relationship. The functional objectives and their needs are taken into account, adapting the intervention to the reality of families and children to improve satisfaction and adherence within it.

Expert consensus on optimal child-led goal setting practices for school-aged children with a disability or delay: An International Delphi Study

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Introduction: Involving children in healthcare decision making is widely endorsed. Evidence exists that children can self-identify achievable goals, which can increase their engagement and improve therapeutic outcomes. However, in practice, children often play a marginal role in goal-setting compared to parents or therapists, and optimal child-led goal-setting practices are not documented. This study aimed to establish expert consensus on child-led goal-setting practices for use with school-aged children (5<18 years) who have a disability or delay.

Methods: A three-round eDelphi survey was performed with 68 expert paediatric clinicians and researchers from nine countries. In Round 1, participants responded to open-ended questions regarding which people, practices and strategies should be involved in optimal child-led goal-setting. Responses were collated and unique items were rated for agreement in Round 2 and 3. Items reaching 85% agreement or disagreement were deemed to have reached consensus.

Results: Half the participants reported finding it difficult to locate information related to child-led goal-setting. However, strong consensus emerged supporting: frameworks guiding effective child-led goal-setting; signs of child readiness for goal-setting; active involvement of children in goal-setting; respective roles of children, caregivers and therapists; steps to follow and strategies to use during child-led goal-setting; additional strategies to assist children with communication and/or cognition impairments; specific tools (or lack thereof) to supportchild-led goal identification, documentation and evaluation; and the value of digital technology.

Conclusion: Results highlight the need further research, resources, and education to support professionals to apply optimal child-led goal-setting, with an emphasis on technology.

Relevance for users and families:

Children are capable of setting and reviewing meaningful self-selected goals in a supportive therapeutic environment. Our Results provide information about the available frameworks, strategies, and clinical tools that professionals can use to support children and families in child-led goal setting practices. Findings also clarify the next steps for research to create clinical tools that improve effectiveness and efficiency of child-led goal-setting, with an emphasis on enabling technology.

Intervention with the CO-OP Approach leads to a transfer effect over time to untrained goals for children with spina bifida and cerebral palsy

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Introduction: Interventions used for children with disabilities should yield sustainable Results. A previous RCT study showed that intervention with Cognitive Orientation to daily Occupational Performance (CO-OP) Approach was more effective than ordinary treatment in terms of reaching goals and solving problems in new situations for children with spina bifida and for children with CP. The present study investigates effects over time of the intervention with CO-OP Approach regarding goal attainment and transfer effects.

Patients and Methods: Second report, evaluating effects over time, from a multi-centre intervention using CO-OP Approach. Thirty-four children (7–16 years) identified four goals (one remained untrained to study generalisation and transfer to new activities) and participated in an eleven-session intervention. Assessments were conducted at baseline, immediately after the intervention and at three-months follow-up using the Canadian Occupational Performance Measure (COPM) (subjective) and the Performance Quality Rating Scale (PQRS) (objective) as primary outcome measures. Executive function and self-rated competence in daily living were also assessed.

Results: Significant improvements in goal attainment for trained goals, both subjectively and objectively, were demonstrated post-intervention and persisted at follow-up. Significant higher goal attainment over time was also seen in the untrained goals on both subjective and objective assessments. Self-rated competence in general activities of daily living increased slightly and was even higher after three months.

Conclusion: CO-OP intervention is effective in achieving and maintaining children's own goals over time. The transfer effect was confirmed by high goal attainment for untrained goals, three months after the intervention ended.

Relevance for users and families:

COOP is a generic approach suitable for many target groups. Through the therapist's reflective questions, the person finds their own specific strategies to achieve their own identified goals using an overall cognitive strategy. In the COOP Approach, the person develops their metacognitive thinking and by being able to transfer the ability to solve performance problems into new situations themselves, the person's sense of competence increases and thus their self-efficacy is enhanced.

The “ENabling VISions And Growing Expectations” (ENVISAGE) program for parents of children with developmental disabilities: a pilot evaluation and feasibility in Croatia

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Introduction: ENVISAGE is a 5-week online program for parents of children with developmental disabilities (DD) (0-6y), initially co-designed in Canada and Australia. This study presents the first international pilot implementation of the program in a new language and cultural settings, in Croatia. We aimed to examine parents’ experiences of participating in the ENVISAGE program in Croatia and determine its implementation feasibility.

Methods: In this qualitative discourse analysis study, participants were invited to take part in 5 online weekly group workshops and review ENVISAGE program materials. Parents who took part in at least 4/5 were individually interviewed after the program’s completion. To assess feasibility, we aimed to recruit and retain a minimum of 8 parents and lead two groups (4-7 parents in each).

Results: From 20 recruited participants, 13 took part in at least 4 out of 5 workshops and completed the study (3 cohorts). Participants’ experiences with ENVISAGE were consistently positive. They particularly valued the peer-exchange and opportunities to connect with other parents of children with DD. They all believed to have benefited from the program’s content and group discussions. All feasibility targets were met.

Conclusions: ENVISAGE is a highly acceptable and feasible online empowerment program for parents of children with DD in Croatia. This study demonstrates that ENVISAGE could be successfully implemented in other language and cultural settings other than the ones in which it was initially developed, which grants its further cross-cultural exploration and international scaling.

Relevance for users and families:

ENVISAGE is a novel empowerment program for parents of children with DD. When new programs are being developed, it is critical to first explore their acceptability and end-users' experience, especially when delivered in a new language or cultural context. This study supports that ENVISAGE is an acceptable and meaningful programs for parents of children with DD in Croatia, which grants its further large-scale exploration.

Identifying barriers and facilitators for participation of children with CP, their siblings, and families in Switzerland: the PARTI-CP study protocol

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Introduction: The international literature suggests that children with Cerebral palsy (CP) participate less in social activities when compared to typically developing peers. Information on how a child with CP affects participation of their siblings and families is largely missing, particularly in Switzerland. Our goal is to gather foundational knowledge about how children with CP, their siblings, and their families participate in Switzerland, identify facilitators and barriers for their participation, and formulate evidence-based recommendations.

Patients and Methods: This mixed-Methods study is nested within the Swiss Cerebral Palsy Registry and includes four work packages (WPs) with qualitative and quantitative elements. In short:WP1, semi-structured interviews with concerned families; WP2, Select and develop quantitative participation assessments for survey; WP3, perform surveys within the registry; WP4, formulate recommendations for improving participation in children with CP, their siblings, and their families.

Results: The project is a collaboration of four Swiss institutions. It was submitted to the Swiss National Science Foundation and accepted in autumn 2022.

Conclusion: Our study will provide details about aspects of participation of children with CP, their siblings, and their families in Switzerland. The perspectives of siblings and the family as a whole will be particularly relevant, as such research is also lacking internationally. Our study Results will serve as a basis for family-centred approaches to optimise participation for children with CP, their siblings, and their families. Recommendations for physicians, therapists, teachers, and organisers of leisure activities will help adapt their services to these families' needs.

Relevance for users and families:

Participation is a major goal for children with CP. We need to hear from them, their siblings, and families directly, about their experience with barriers and facilitators in everyday life. Consequently, we gain knowledge that supports the clinicians and the children and their families to set goals and treatment plans together, that are useful for their daily lives. Hence, our study generates real-world knowledge based on real-world experience.

Mini-Symposium: Early intervention in neurodevelopmental disabilities (EIDD) in Europe: sharing experiences within the EACD sponsored EIDD Special Interest Group

Andrea Guzzetta[1,2], **Olena Chorna**[2], **Lisa Mailleux**[3], Nathalie De Beukelaer[3], **Gosia Jon-Dare**[4], Jenny Carroll[4], **Carmen Lillo-Navarro**[5,6], **Sally Jary**[8,9], Anna Basu[9,10], **Christina Hoei-Hansen**[11], Gija Rackauskaite[11]

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- The Early Intervention in Developmental Disabilities Special Interest Group (Andrea Guzzetta) 10 min
- When the risk for cerebral palsy is high from the start: early intervention in the NICU, experience from an Italian network. (Olena Chorna) 10 min
- The importance of infant mental health in the context of early intervention. Experience from the Belgian context (Lisa Mailleux and Nathalie De Beukelaer) 10 min
- A Welsh perspective - 'Better Start, Better Future' early intervention programme at Cerebral Palsy Cymru in Wales (Gosia Jon-Dare and Jenny Carroll) 10 min
- Early intervention in Spain: Results of a National survey among Spanish pediatric physiotherapists. (Carmen Lillo-Navarro) 10 min
- The Ei SMART approach:Overview, dissemination and resources in the UK (Sally Jary and Anna Basu) 10 min
- Cerebral Palsy Early Detection and Intervention Trial (CP-EDIT), a new framework for implementation of early intervention in Denmark (Christina Hoei-Hansen and Gija Rackauskaite)
- Discussion and Conclusions (all presenters) 20 min

Relevance for users and families:

All experiences of early intervention presented in this mini-symposium are strongly focused on the central role of care-givers and families, from the start, and all contributions will include the parental perspective.This is in line with the principles of all international guidelines and recommendations on early intervention in developmental disabilities that inspire the work of the special interest group.

Oral Communication: Pain

Pain induced by interventions and daily care in children with cerebral palsy: an observational study.

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Introduction: Pain is a common comorbidity in children with cerebral palsy (CP). At this time, little is known about acute pain induced by interventions and daily care provided in pediatric centers. Objectives were to determine the incidence of care-related pain, to identify risk factors and preventative measures used by professionals.

Patients and Methods: 101 children with CP (mean age: 12years ±3; 49M and 52F) were randomly selected in French pediatric rehabilitation and special education centers. The FLACC-r scale was used to evaluate pain during each care or intervention that required physical contact on the child (named physical act), for five consecutive days and 1 night. Demographics and clinical data, type of physical act, pain prevention and institutional settings were collected.

Results: 2704 physical acts were recorded, 8% induced pain and 54% of children with CP experienced at least one painful act during the study period. The most often painful were personal care (feeding, standing, transfer) and physiotherapy (stretching, mobilizations, massage). Level of physical disability (GMFCS levels) and physical acts (personal, nursing care and physical therapy) were determinant for care-related pain ($p<0.01$). Pain prevention was only used for 25% of acts.

Conclusion: Care-related pain occurs daily for children with CP during their stay in pediatric centers. Children with CP with a high level of motor dependency were most at risk for pain.

Relevance for users and families:

All professionals and caregivers who are involved in the care of children with CP in institutional settings must be aware of the issue of pain, and that pain can be induced by even the most routine physical act. Although pain is described as the most frequent comorbidity, its management needs to be improved through a focus on pain prevention, assessment, and family-professional partnership.

Pain and discomfort related to therapeutic interventions provided to the children with physical disabilities in pediatric centers: prevalence, prevention and risk factors

Amandine Dubois[1,2], Emmanuelle Courtois-Communier[3,4], Arnaud Brasseur[6], Sylvain Brochard[3,5,6]

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Introduction: The daily life of children with physical disabilities is organized around interventions and therapies. Objectives were to provide an exhaustive description of the therapeutic interventions provided in pediatric centers; determine the incidence of pain and discomfort related to these interventions, and to identify risk factors and preventative measures used by professionals.

Patients and Methods: 280 children with physical disabilities (mean age: 12years ±4; 144M and 136F) were randomly selected in French pediatric rehabilitation and special education centers. The FLACC-r scale was used to evaluate pain (score >4/10) and discomfort (score [1-4[/10) during each therapeutic intervention that required physical contact on the child, for five consecutive days and 1 night. Four types of therapeutic interventions were assessed (physiotherapy, occupational, speech and language therapy, adapted sports). Demographics and clinical data, pain prevention, and institutional settings were collected.

Results: 1362 interventions were recorded. Among them, 7.5% induced pain (mean score=5/10) and 17% induced discomfort (mean score=1.9/10). Interventions related to physiotherapy (mobilizations, stretching and massage) were the most often painful (>10%) and uncomfortable (>20%). Oral stimulation was only uncomfortable (41% of acts). Level of dependency was a risk factor for pain ($p<0.01$). Some differences were also reported according to the pediatric centers. Pain prevention Methods (mostly distraction, paracetamol, morphine) was only used for 30% of acts.

Conclusion: Therapeutic interventions provided to children with physical disabilities in pediatric centers can induce pain and discomfort, particularly some acts in physiotherapy.Children with a high level of dependency were most at risk for induced pain.

Relevance for users and families:

Children with physical disabilities hospitalized or attending a day hospital for several consecutive weeks or months experience repeated pain and discomfort during their stay. Strategies are required for improving the management of pain and discomfort during therapeutic interventions in pediatrics centers. They must be developed taking into account the children's age, their psychological and medical characteristics, and family-professional partnership.

Biofeedback assisted relaxation training vs distraction therapy for procedural pain management in children undergoing botulinum toxin injections

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Introduction: This study compared biofeedback assisted relaxation training (BART) versus distraction therapy as non-pharmacological alternatives for procedural pain management during botulinum neurotoxin A (BoNT-A) injections.

Patients and Methods: This was a crossover randomized controlled trial. Eligible participants were 7 years and older with neurological disabilities. Participants were randomized to BART or distraction during their first BoNT-A treatment, followed by the alternative intervention in their subsequent treatment. BART was provided via BrightHearts, an interactive heart rate responsive application. Outcomes were pain (Faces Pain Scale –Revised), fear (Children's Fear Scale), and anxiety (numerical rating scale, State–Trait Anxiety Inventory). Demographics, paired t-tests, and linear mixed models were used.

Results: Thirty-eight participants (mean [SD] age 13 years 5 months [3 years 4 months], 20 males, 34 with cerebral palsy) completed both interventions. There were non-significant differences in overall pain (mean difference − 0.05, 95% confidence interval [CI] −0.91 to 0.80, $p = 0.902$) and worst pain (mean difference 0.37, 95% CI −0.39 to 1.13, $p = 0.334$) when using BART and distraction therapy. There were non-significant differences in fear and anxiety between interventions. Younger age, higher pre-procedural state anxiety, and Gross Motor Function Classification System (GMFCS) levels III and IV were associated with worse outcomes ($p < 0.05$). Participants who used BART before distraction therapy reported lower pain and anxiety scores for both BoNT-A treatments ($p < 0.05$).

Conclusion: Participants reported similar pain when using BART and distraction therapy. Those who used BART first reported lower pain and anxiety during both treatments.

Relevance for users and families:

The acceptability of both interventions emphasizes the need for more research exploring non-pharmacological interventions for procedural pain management.

Non-pharmacological strategies may be helpful for children with neurological physical disabilities during other painful medical procedures.

Younger children, those with higher pre-procedural state anxiety, and those functioning at GMFCS levels III and IV had a worse experience, highlighting priority groups for further clinical and research interventions.

Elliptical training as a modality to promote physical activity in children with cerebral palsy GMFCS level V: A Single Case Experimental Design

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Introduction: Providing opportunities to engage in safe physical activity for school-aged children classified within Gross Motor Function Classification System (GMFCS) level V can be challenging. We aimed to determine the feasibility of elliptical training on personalised health and well-being outcomes.

Patients and Method: In a Single Case Experimental Design, target behaviour measured on the Goal Attainment Scale was evaluated over a baseline (randomised between 5 and 9 weeks) and intervention (6 weeks) phase in ten children (mean age 13.4y; SD 3.9y; GMFCS V). This co-designed program consisted of 3,50-minute sessions a week for 6 weeks with each session involving active time on the elliptical trainer with partial body weight support. Target behaviour was analysed by visual and statistical analysis through change in means, 2 SD band method, Percentage of Non-Overlapping data and Tau-U. Impact of treatment was classified as positive if visual analysis was supported by statistical analysis.

Results: Sessions were well attended (mean=16 sessions) with no adverse events reported. 73% of goals were at the body structure and function level. Of these goals, positive impact of treatment was found in 54% of target behaviours which included sleep, alertness, fitness, pain, comfort and constipation.

Conclusion: Our Results support the feasibility, acceptability and potential efficacy of elliptical training as a movement option for children with GMFCS level V to address health and well-being outcomes.

Relevance for users and families:

Relevance for Users and Families: This supports the importance of movement to address goals even in children with GMFCS level V, within a 24-hour activity approach.

Psychologycal symptoms of cooping with chronic pain in children and adolescents

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Introduction: Chronic pain is a continuous or recurrent pain that persists beyond the expected normal time of healing, lasting three months or longer. The prevalence of chronic pain in children and adolescents is about 30%. Most often, headaches, stomach-aches and body pain are reported. Longer lasting coping with chronic pain leads to different psychological consequences, difficulties in social life and school absenteeism.

Patients and Methods: The aim of our paper is to establish and investigate psychological consequences of chronic pain in 25 children and adolescents with the average age 15,2 years (SD = 2,1). All of them were examined by the physical and rehabilitation medicine specialist and meet criteria for chronic pain. We assessed their current psychological wellbeing through self-evaluation (The Revised Children's Anxiety and Depression Scale – RCADS, Fear of Pain Questionnaire, Child report - FOPQ-C, The catastrophizing scale – child version - PCS-C) and parent reported behaviour (Child Behavior Checklist for ages 6–18 years - CBCL).

Results: The Results were compared against the normative data. Our participants reported on clinically higher rates of separation anxiety and more pronounced depression symptoms. Because of chronic pain, they more often avoid physical activity, deal with emotions of fear and think about pain increase through activity. Their parents report about similar consequences of chronic pain. Anxiety and depressive symptoms, somatisation, difficulties in social relationships and copping with stress are rated as statistically more present in comparison to healthy children.

Relevance for users and families:

We conclude that all participants deal with psychological consequences of chronic pain (especially anxiety and depression). The awareness of psychological consequences in long term chronic pain and a detailed assessment are crucial for planning further psychological treatment and therapy.

Pain sensitivity is associated to emotion and behavior impairments in children with autism spectrum disorders

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Introduction: Somatosensory and emotion impairments are important comorbidities in children with autism spectrum disorders (ASD). This study aimed at exploring the relationship between different aspects of emotion processing (knowledge, regulation and behavior) and the sensitivity to sensory stimuli in children and adolescents with ASD, compared to typically developing peers (TDP).

Materials and Methods: Thirty-eight children and adolescents with ASD and 34 TDP completed a task on emotion knowledge, based on the recognition of affective facial expressions. Somatosensory thresholds of touch, pain, heat and cold were registered in the hand palm and dorsal part of the forearm. Parents completed questionnaires on emotion regulation, behavior and sensory profile.

Results: Children with ADS had lower sensory responsiveness than their TDP. Although both groups reported similar frequency of chronic pain, children with ASD had lower cold pain thresholds and pressure pain thresholds than their TDP. Touch and temperature thresholds were similar in both groups, as well as emotion knowledge, emotion regulation and behavior problems. In children with ASD, high pain sensitivity was associated with low emotional knowledge and more internalising and externalising problems. In both groups, lower sensory responsiveness was related to higher emotion regulation and lower emotion lability.

Conclusions: Children with ASD are specially prone to have enhance pain sensitivity. In children with ASD, pain sensitivity and sensory impairments seem to interact with emotion and behavior. Future studies should deepen in the relationship between somatosensory and emotion processing in children with ADS.

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Relevance for users and families:

Relevance for users and families: Children with autism spectrum disorders (ASD) have higher pain sensitivity than their typically developing peers. Pain sensitivity seem to be related to different aspects of emotion processing and behavior. Assessment and global interventions focused on reducing pain sensitivity and improving the different aspects of emotion processing should be considered for preventing abnormal interactions of these comorbidities in childhood and adult age.

Instructional Course: Hip Joint Orthopedic Treatment with Dega Transiliac Osteotomy In The Hip Subluxation and/or Dislocation in Spinal Muscular Atrophy

Marek Jóźwiak [1], **Bartosz Musielak**[1], **Magdalena Ratajczyk**[1]

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Purpose: To review the overall treatment approach to hip joint instability in SMA called as proactive or reactive treatment.

Target Audience: This course is relevant to all orthopaedic surgeons, neurologists, PT's carring for SMA patients withhip joint subluxation or dislocation and for all who are dealing with pediatric hip disorders.

Course summary: The presence of hip dislocation or subluxation in the SMA population is the result of muscular reasons due to muscular imbalance; To restore this pathology the soft tissue surgery and reconstructive procedures of pelvis and femur must be combined together to gain the stable hip joint reduction and reconstruction of the external forces generated by spastic muscles through the bones and joint capsule into joint surfaces.

The Dega transiliac osteotomy combined with proximal femur osteotomy and/or some selected soft tissue procedure are the most common procedures perform in the treatment of acetabular reconstruction in SMA – hip joint dislocation.

Topics addressed will include the historical aspects of hip instability treatment in pre-pharmacology - treatment era , and post pharmacology-treatment.

During the course all participants will have the opportunity to comment and discuss the surgery video recording and animation presentation, transfer their experience on hands – on excercises (swawbones cases).

Learning objectives:

- identify indications and contraindications for surgery treatment
- understand the three-dimensional basics of acetabulum deformity and spatial correction of it
- acquire basic and advanced concept of Dega osteotomy with its surgical tips & tricks
- complete transiliac osteotomy technique effectively

Relevance for users and families:

- identify indications and contraindications for surgery treatment
- understand the three-dimensional basics of acetabulum deformity and spatial correction of it
- acquire basic and advanced concept of Dega osteotomy with its surgical tips & tricks complete transiliac osteotomy technique effectively

Mini-Symposium: From muscle mitochondrial function to aerobic capacity – using Framerunning to understand exercise physiology in cerebral palsy

Ferdinand von Walden[1], **Annika Kruse**[2], **Linnea Corell**[1], **Henrik Eriksson**[3], **Sudarshan Dayanidhi**[4]

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Learning Objectives

- Understand determinants of aerobic capacity and skeletal muscle bioenergetics.
- Learn about mitochondrial bioenergetic dysfunction in skeletal muscles and exercise capacity of individuals with cerebral palsy (CP).
- Highlight current recommendations for physical activity (PA) in children and adolescents with CP.
- Discuss how Framerunning can help individuals with moderate to severe CP to perform high intensity exercise.

Summary: This session will introduce cardiorespiratory exercise physiology and energy producing factors in working skeletal muscle. Secondarily, we will discuss the impact of exercise on mitochondrial function, and recent evidence illustrating potential mitochondrial dysfunction in skeletal muscles in children with cerebral palsy. Thirdly, we will provide an overview of current state-of-the-art on aerobic capacity in individuals with CP and integrate how Framerunning could be a way of reaching the current recommendations for PA.

Outline of the symposium

- FvW (15 mins): An overview of the planned session and discuss general concepts in exercise physiology and cellular bioenergetics.
- SD (15 mins): Information on mitochondrial function, recent evidence for alterations in CP skeletal muscle, and how this might potentially affect skeletal muscle function and exercise capacity.
- LC (15 mins): An overview of aerobic capacity in individuals with CP and new data on exercise capacity in individuals with CP and GMFCS levels II-V.
- AK (15 min): Information about how to use Framerunning to reach physical activity recommendations for individuals with motor impairments.
- HE (15 min): Personal story about Framerunning with insights both from recreational training and international competitions.
- Moderated discussion (15 mins)

Relevance for users and families:

This session will describe current recommendations for physical activity (PA) in children and adolescents with CP and discuss how Framerunning can help individuals with moderate to severe CP (GMFCS II-V) to perform high intensity exercise and training.

Mini-Symposium: Shared decision making: opportunities and concepts in the care of individuals with cerebral palsy

Laurie Glader[1], **Nathan Rosenberg**[1], **David Frumberg**[2]

[1]The Ohio State University College of Medicine, Columbus, United States, [2]Yale School of Medicine, New Haven, United States

Objectives:

- Participants will describe elements of shared decision making
- Participants will list ways to remove provider bias from a shared decision-making model
- Participants will explain how goal setting and participation can be used as measures in a risk/benefit discussion
- Participants will define the concept of time toxicity
- Participants will identify opportunities to employ shared decision making when caring for individuals with cerebral palsy

Summary: Paternalism and shared decision making (SDM) represent opposite ends of the spectrum when it comes to clinical decision making. While medicine is shifting towards SDM, empowering people and caregivers in clinical settings remains challenging. The process becomes an art of shared goal setting, active listening, bias awareness and presentation of perceived risks and potential benefits. This symposium will review the SDM evidence regarding effectiveness in generating trust and goal achievement, and address topics frequently unnamed in SDM such as time toxicity and participation. Cases incorporating common decisions encountered in the care of individuals with cerebral palsy will be presented, illustrating approaches to SDM and tools to address provider bias. Caregiver perspective will be integrated into the symposium through pre-recorded videos and will also be sought from the audience. Active participation from all attendees will be encouraged throughout.

Outline of the symposium:

- Laurie Glader (Complex Care) – Introduction and elements of SDM (12 min)
- Nathan Rosenberg (PM&R) - Bias and goal setting(10 min)
- David Frumberg (Orthopedics) - Time toxicity (David) (10 min)
- Case discussion, including audience participation -(all) (28 min)

Relevance for users and families:

Individuals with cerebral palsy and those that care for them encounter repeated moments of decision making, often around potential interventions.This symposium addresses mechanisms to strengthen the collaboration between individuals, caregivers and their health care providers in navigating those critical moments in decision making.

Oral Communication: Advances in Technological Support 1

Pre-operative gait pattern seems to influence the effect of selective dorsal rhizotomy on gait in children with spastic diplegia

Liza Van Dijk[1,2], Kirsten Veerkamp[1,2,3,4,5], Marjolein van der Krogt[1,2], Mariam Slot[6,7], Annemieke Buizer[1,8]

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Introduction: Some children with spastic diplegia are eligible for selective dorsal rhizotomy (SDR) surgery. However, selecting individuals who benefit most from surgery remains challenging. The aim of this study was to evaluate how different pre-operative gait patterns change after SDR in children with spastic diplegia.

Patients and Methods: Nineteen children with 3D gait analysis before and two years after SDR were extracted from the in-hospital database. A cluster analysis was performed to distinguish different gait patterns based on sagittal hip, knee and ankle angles pre-SDR. Deviations from typical gait per leg pre- and post-SDR were quantified by the gait profile score (GPS; [1]). Scores were compared pre- and post-SDR by Wilcoxon signed-rank tests, and the pre-post difference was compared between clusters by Mann-Whitney U tests. Changes above 1.6 degrees were considered clinically meaningful[1].

Results: Three pre-operative gait patterns were extracted, with (1) increased knee flexion during stance (18 legs), (2) knee extension and increased ankle plantarflexion during stance (14 legs), and (3) increased knee flexion and ankle plantarflexion (6 legs). GPS changed from 12.5±3.0° to 9.4±2.7° for the first gait pattern (p=0.002) and from 17.9±1.6° to 11.2±3.0° for the third (p=0.028). The second gait pattern did not change significantly (pre: 12.8±3.1°; post: 11.6±2.5°; p=0.25). The third gait pattern improved significantly more than the second (p=0.011).

Conclusion: Gait kinematics seems to improve differently after SDR among distinguished pre-operative gait patterns.

[1] Baker, McGinley, Schwartz, Thomason, Rodda, Graham. The minimal clinically important difference for the Gait Profile Score. Gait Posture. 2012;35(4):612-5

Relevance for users and families:

Relevance: Pre-SDR gait pattern may be predictive for gait changes after SDR.

Effectiveness of rigid spinal orthoses to improve sitting in dyskinetic cerebral palsy: a pilot study

Ellen Van Wonterghem[1], Meta Nyström Eek[2], Anna-Klara Nohlin Sandsjö[4], Anja Sundemo[4], Helga Haberfehlner[1], Elegast Monbaliu[1], Kate Himmelmann[3,4]

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Introduction: Individuals with dyskinetic cerebral palsy (DCP) often have severe problems sitting independently. Impaired trunk control may lead to scoliosis, requiring daily use of spinal orthoses to avoid further progression. This study explored the immediate impact of these orthoses on sitting function in individuals with DCP.

Patients and Methods: Eight individuals with DCP and GMFCS levels III-V (10y10m, STD 3y8m) were analyzed with and without rigid spinal orthosis sitting on a bench for 90 seconds. If needed, support was given at shoulder level. Pressure mapping was used to assess their seated pressure distribution, from which center of pressure (CoP) distance, seat-load symmetry, anterior-posterior and left-right sway was retained. Wilcoxon signed rank tests ($p<0.05$) and effect sizes (ES) were performed to compare with-without orthosis status.

Results: Sitting with and without orthosis did not reveal any significant differences measured by pressure mapping (Seat-load symmetry ($p=0.123$; ES=0.452), anterior-posterior sway ($p=0.208$; ES=0.524), CoP distance ($p=0.401$; ES=0.568) and left-right sway ($p=0.779$; ES=0.059)).

Conclusion: Overall, no significant effect of rigid spinal orthosis treatment was found on sitting function in individuals with DCP. Participants tended to improve in seat-load symmetry using spinal orthoses. However, a negative impact was found on stability factors such as CoP distance and sway. This study was a first exploratory study for which evaluation in a larger dataset is needed. In future, inclusion of other variables and Methods is advised to improve the understanding of orthosis treatment on sitting function as well as its potential impact on head and upper limb function.

Relevance for users and families:

In this study we explored the immediate impact of spinal orthoses on sitting function in individuals with DCP. First, our Results indicated a slight shift towards more symmetrical sitting, which in the long term may benefit their musculoskeletal health. In contrast, sitting stability tended to worsen. Second, large interindividual differences were observed. This study improved population-level insights on sitting function in DCP, which may result in a more individualized treatment approach addressing these differences.

Quantifying abnormal loading within the foot of children with spastic cerebral palsy to understand the development of foot deformities

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Introduction: Many children (>90%) with cerebral palsy (CP) develop a foot deformity, which affects their mobility. Gait analysis is used to assess dynamic foot function. Until now only motions within the foot could be studied, while deformities are caused by a disturbed interplay of forces due to muscle actions and external loading. The aim of this study is to quantify the foot and ankle joint moments to better understand the development of various foot deformities in children with CP.

Patients and Methods: So far, 17 children with spastic CP were included, of whom 27 feet were analyzed (neutral:11, planovalgus:7, cavovarus:4, equinovarus:5). All children underwent gait analysis to quantify the internal moments of the ankle, Chopart, Lisfranc and metatarsophalangeal joints. Outcomes were compared between each foot type and a reference dataset of 13 typically developing (TD) children with 1D statistical parametric mapping.

Results: Distinct differences in kinetics were present between the different foot types and TD data, like an increased ankle plantar flexion moment in equinus feet, increased ankle and Chopart eversion moment in varus feet and increased Chopart adduction moment in valgus feet. The increased moments were caused by changes in center of pressure and moment arms due to the altered foot alignment.

Conclusion: Internal moments in the ankle and foot were often opposite to the abnormal foot alignment (e.g. eversion moment in varus foot). This indicates that not internal muscle forces, but rather altered external loading due to abnormal foot alignment contributes to the further development of foot deformities.

Relevance for users and families:

The Results of this study give insight in the factors that explain and potentially predict the development of foot deformities in children with CP. In the future, this will allow better prevention or intervention at an early stage with the goal to maintain walking ability. It seems that mainly the foot alignment contributes to abnormal loading of the foot, which highlights the importance of proper footwear with adequate foot correction.

Frame Running as sports; fitness, friends, fun and more; ticking all the boxes of the F-words model in childhood disability

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Introduction: A running frame is a three wheeled frame with steer, chest plate and saddle, which makes it possible that persons which mobility limitations can walk or run. Frame Running is available as sports in theNetherlands.This study explores the experiences of young athletes and their parents about the impact of Frame Running on their lives.

Participants and Methods: Semi-structured interviews were conducted with 24 parents of Frame Running athletes (5-18 years, GMFCS II-IV) and 14 Frame Running athletes themselves. . The interviews were recorded and transcribed verbatim. Two researchers coded these transcriptions. Thematic analysis was used to recognize relevant topics for athletes and their parents using the F-words model in pediatric rehabilitation (inspired on ICF-CY).

Results: Athletes and their parents reported an positive impact of Frame Running on all domains: Fitness (ICF body function): increased cardiovascular fitness and strength; Function (ICF activity): improved walking and Frame Running; Friends (ICF participation): making new friends and participate at their club,playing outside with friends (at home). Family (ICF external factors): family gets more interest in sports, siblings often train with their brother/ sister. Fun (ICF internal factors): improvements in concentration, self-confidence and perseverance.Children liked Frame Running very much. Future: many children dreamed of participation in competitions in the future or even in Paralympic games.

Conclusion: Frame Running has many benefits for young athletes according to their parents and themselves at all domains of the F-words model. Frame Runningsupports participation and inclusion of children with a disability in society.

Relevance for users and families:

Pediatric physical therapist can play a key role in implementing Frame Running in their therapy or as a sports for children with disabilities. For those children the frame gives many new opportunities for participation in leisure activities with their family and friends. Children and parents who know the frame are very enthousiastic. So all children and parents around the globe should be able to know and use the running frame.

Automatic identification of infants with cerebral palsy using smart phone videos

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Introduction: The General Movements Assessment (GMA) is a good predictor of cerebral palsy (CP), based on grading infants spontaneous movements at 3months1. A rate-limiting factor for large-scale screening is access to trained GMA assessors. Recent advances in video-based pose estimation algorithms may make it feasible to automate GMA scoring from videos. The aim of this study was to predict GMA ratings from videos using infant movement data.

Patients and Methods: We analysed 505 videos from 327 infants acquired at 12-18weeks post-term: 158 extremely premature infants (<28weeks gestation) and 169 term-controls (>37weeks gestation). Based on Prechtl's GMA, two trained assessors independently scored each video.

We trained a deep-learning model, DeepLabCut, on 500 labelled infant images to detect 18 key-points. We processed key-points to remove outliers, fill gaps, correct for camera movement, and adjust for infant size. Our GMA classifier used 1D convolution neural networks to identify infants with absent/abnormal movements. Train (70%), validation (15%), and test (15%) datasets were used for model training. Over 25 folds, we report area under the curve (AUC), balanced accuracy, and positive and negative predictive power (PPV & NPV).

Results: Root mean square difference between computer and human labelling was 4.4pixels. The GMA classifier achieved (mean±S.D) an AUC 0.79±0.08, balanced accuracy 0.70±0.08, specificity 0.65±0.08, sensitivity 0.76±0.15, NPV 0.94±0.04 and PPV 0.28±0.08.

Conclusion: We tracked infant movements and predicted GMA in infants at 12-18weeks. Our model correctly identified abnormal movements in 70% of infants. At a population level, our work highlights the potential for automated CP screening.

Relevance for users and families:

Our work has the potential to improve access to early detection of cerebral palsy in infants through large-scale screening. Detecting problems early is vital for fast-tracking early intervention, which is shown to improve a child's physical and intellectual abilities as well as protect parents' mental health.

System for Early Neurological Deviation Detection (SENDD) – ongoing project Results

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Introduction: General movements (GMs) assessment is a reliable method of gestalt evaluation of movement complexity and variation with high predictive value to identify neurological issues which may lead to cerebral palsy or minor neuromotor dysfunction. The quality of GMs in the fidgety period has been found to have the highest predictive value.

Patients and Methods: We included more than 700 videos (still increasing) of infants in fidgety age collected institutionally or by smartphone camera/app assisted in home-setting. All videos were checked for inclusion and exclusion criteria depending on technical and child requirements. All collected videos were evaluated by trained professionals using the Hadders-Algra system. For GMs annotations and assessments 25 different machine learning (ML) models and algorithms (AI systems) were consecutively tested.

Results: Fully developed and reliable 15-keypoint annotation tool. Home video can replace institutional recording and be a reliable source of videos. For this purpose, WEB and MOBILE APPS were developed. The most reliable and trainable neural networks were selected. Accuracy of AI Conclusions compared with trained human assessments for Hadders-Algra 4-category system and screening toll using only2-category system (normal, abnormal).

Conclusion: Most reliable ML models with the best precision and accuracy Results are DensNet169 (pose estimation & computer vision) and CNN (GM assessments, in 4-category (65%) and 2-category system (80%)). Higher accuracy is directly related to the number and diversity of videos used for training, as annotation time was reduced.

Relevance for users and families:

System for Early Neurological Deviation Detection is a widely available and easy-to-use solution that saves medical resources and time as effective screening tool both for professionals and families.

Mini-Symposium: Promoting health, empowerment, and resilience in parents of disabled children: an exploration of novel caregiver-focused interventions

Christopher Morris[1], **Annabel McDonald**[1], **Peter Rosenbaum**[2], **Helen Bourke-Taylor**[3], **Natalie Elder**[3], **Christine Imms**[4]

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Objectives: To highlight the emerging field of parent caregiver-focused interventions.

Summary: Parents have to rise to the multiple demands of caring for disabled children: numerous medical appointments, unanticipated relationships with health and other professionals, constant uncertainty. They face increased risk of mental and physical health problems by prioritising their children's care and neglecting themselves.

There is an exciting field of parent carer-focused interventions, at different stages of development and evaluation. These aim to (i) teach parents about childhood disability, (ii) empower them in their interactions with professionals, (iii) share caregiver skills, and/or (iv) promote health and wellbeing. Facilitators vary between professionals and/or trained parent caregiver peers. Some programmes focus on mothers, others on all parents, or on the family.

Outline of the symposium:

We will present three programmes being delivered in Australia, Canada and UK, and recognise other programmes delivered around the world.

- Healthy Mothers Healthy Families programs involve in-person/online workshops or individualised coaching to impact maternal health behaviours, family participation and empowerment.
- ENVISAGE is an 'early intervention program for caregivers' involving online workshops focusing on a strengths-based approach to promote empowerment in relationships with wider family and services.
- Healthy Parent Carers is a peer-led, group-based, modular in-person or online programme that encourages actions associated with health and wellbeing.

Commonalities in design, delivery and evaluation, as well as challenges, will be unpacked. We expect our collaborative approach with complementary and not competing interventions will accelerate our collective goal of healthy, empowered, and resilient parent carers.

Relevance for users and families:

The parent caregiver-focused interventions we will describe have been co-created with people with lived experience for their peers. We include parent carrers who are people with lived epxerience as co-presenters.

Mini-Symposium: Modern interdisciplinary pediatric palliative care of children and adolescents with different types of disabilities

Anamarija Meglič[1], **Nataša Šuštar**[1], **Majda Oštir**[1], **Petra Lešnik Musek**[1]

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Objective: Every child and adolescent living with a life-limiting or life-threatening condition should receive pediatric palliative care (PPC) to alleviate suffering and enhance their quality of life. The integration of PPC should become a standard of care for all.

Learning objectives of the course: In Slovenia, most children with uncurable conditions who also have different types of disabilities are identified at the University Children's Hospital in Ljubljana. A few years ago, a hospital interdisciplinary PPC team was established. It offers PPC consultation, help in advance care planning, and advice in providing support to families. Early identification and inclusion of patients in early PPC means the greatest benefit to them because many worsening conditions and suffering therefore could be prevented. PPC team successfully carried out the short education in all wards to raise awareness of PPC's importance. It was achieved that different medical teams request the hospital PPC team's cooperation and consequently, we all help to ensure that children are exposed to a minimum amount of suffering.

Target audience: Health care providers of various profiles; physicians, nurses, psychologists, physiotherapists, occupational therapists, and others.

Summary: The integration of PPC should become a standard of care for all. In the course it will be demonstrated on which way the hospital interdisciplinary PPC team at the tertiary level children's hospital offers PPC consultation and help in optimal care for patients and families for those living with an uncurable life-limiting condition and different types of disabilities.

Relevance for users and families:

Improving health care of child and adolescent living with a life-limiting or life-threatening condition with different types of disabilities to enhance their quality of life in the light of the motto ofthe 35th European Academy of Childhood Disability (EACD) Annual Meeting "Smarter Goals for Better Future".

Instructional Course: Let's not re-invent the wheel: Scalability of a training program in family engagement in research across countries

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Objective: To share the lessons learned from a training in family engagement in research program and its scalability across countries

Learning Objectives:

- Increase knowledge on how family members and researchers can meaningfully partner throughout the research process
- Build awareness of the value and need for training in family engagement in research
- Identify opportunities for collaboration to build worldwide capacity for training

Target audience: Researchers, individuals with lived experience of disability and their families, health care professionals

Summary: There is growing recognition of the importance and benefits of meaningful engagement of families throughout the research process. However, it is not self-evident how to partner in research.

In 2018, a Canadian-based 10-week online course on Family Engagement in Research (FER) was co-created with researchers and parents. Since then, 10 cohorts and >300 family members, researchers, and graduate students have been trained. Over the past year the FER Course has been scaled beyond Canada, including an opportunity to collaboratively adapt and translate the FER Course in the Netherlands. In this instructional course, we will share the experiences of, and lessons learned by, researchers and families in the Netherlands and in Canada.

Outline of the course:

- **Introduction** and background
- Discuss common challenges of family engagement in research
- Summarize content of the FER course
- Describe the adaptation and translation process to create a Dutch version of the FER course
- Interactive discussion on opportunities for collaboration to build worldwide capacity in training on family engagement in research

Relevance for users and families:

Thereis growing recognition of the importance and benefits of meaningful engagement of families in childhood disability research. However, it is not self-evident how to partner in research. Issues like How to engage families throughout the research process, How to recognize and deal with barriers and

facilitators to engagement, and Ethics surrounding engagement, are important. In this instructional course, we will share experiences and lessons learned of researchers and families.

Instructional Course: From guideline to proven practice: the road to implementation and innovation

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Objective: Providing a guideline is a good step in providing evidence-based care, however, it does not change clinical practice at once. The objective of this course is to teach Methods for translation of scientific knowledge and implementation of guidelines into daily practice, based on the experience of the allied CP organizations in The Netherlands.

Learning objectives of the course:

- Gaining knowledge about organization of CP care and a continual improvement cycle
- Knowing the steps of implementation
- Identifying how to implement scientific knowledge and guidelines in your organization

Target audience:

Healthcare providers, people with lived experience, researchers, managers, policy makers

Summary: The Netherlands CP organizations will explain what they have done in recent years to achieve the translation of scientific knowledge into rehabilitation practice and to innovate care. Since 2006, a multidisciplinary CP guideline is available. Implementation projects were started by a network of Knowledge Brokers. The CP register provides a standardized framework for follow-up and evaluation of interventions. Personalized care and shared goal setting are important elements.Typical for the efforts is the collaboration of experts with lived experience of CP, healthcare providers and scientists. The desired implementation in daily practice is a leading motive.

Outline of the course:

- Organization of CP care in The Netherlands, including guidelines, knowledge brokers, data registry and involvement of the patient organization
- Learning about steps of implementation and factors related to success or failure
- Implementation exercise with the audience

Presenters: expert with lived experience, healthcare provider, researcher, coordinator, manager

Relevance for users and families:

The Netherlands CP organizations, including the patient organization, will show what they have done in recent years to achieve the translation of scientific knowledge into rehabilitation practice and to innovate care.Personalized care and shared goal setting are important elements.Typical for the efforts is the collaboration of experts with lived experience of CP, healthcare providers and scientists. The desired implementation in daily practice will be the focus of the instructional course.

Instructional Course: From activity to participation: Meaningful goals, better futures

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Learning objectives:

- To understand link between activity and participation
- To consider an intervention that provides that link between skill acquisition and participation through meaningful goal setting, generalization and transfer

Target Audience: This workshop will be suitable for clinicians and researchers in any area of neurodisability, both adult and paediatric populations. Specifically, OTs, PTs, psychologists, neurologists, paediatricians.

Course Summary: With the shift in paediatric neuro-rehabilitation to focus on interventions that address activity and participation, new therapeutic approaches, such as the Cognitive Orientation to daily Occupational Performance (CO-OP) Approach, are being developed and tested in children and young people with neuro-disabilities.

CO-OP specifically focuses on increasing activity and participation rather than redressing impairments.The key difference between CO-OP and other motor learning approaches is CO-OP's unique focus on using problem-solving techniques to achieve child-chosen goals.

Course Outline: We will draw on the expertise of researchers working with populations including developmental coordination disorder, Cerebral Palsy, and movement disorders to begin to elucidate the principles that drive motor skill acquisition and performance in these populations. We will illustrate how meaningful and ambitious goal setting underpins this intervention, and skill acquisition promotes participation via generalisation and transfer.

Videos will be shown to exemplify some of the salient ingredients of CO-OP intervention and activity performance changes. The session will be interactive;participants willanalyse video-taped performance.Participants will acquire basic skills in the use of dynamic performanceanalysis and guided discovery.

Relevance for users and families:

This low-cost intervention will be presented via videos of ambitious goals.

A young person who have received the intervention describe it as: 'you will never understand how much confidence this has given me. I literally feel like I can do anything now'

A parent describes it as: 'without this intervention she probably would have always been, or definitely, a lot more reliant in other people'

Instructional Course: Improving children's motor and social skills with the Animal Fun program

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Objective: This instructional course will be practical, engaging, and interactive for all participants by demonstrating how the practice of motor skills can be fun and engaging for children by using imitation and imaginary play.

Learning Objective of the course: To increase awareness of the importance of early intervention and the effectiveness of this evidence-based program. Participants will leave with many ideas for making movement fun!

Target Audience: Paediatric health professionals, early childhood educators and families.

Summary: Having well developed motor skills are important for all children, but particularly for children with disabilities as these skills form part of the foundation for learning, self-esteem, confidence and social interactions.

Animal Fun (Piek et al 2013, 2015) was developed by a team of allied health professions in Australia. The program was evaluated with three years of randomised controlled trial research and Results showed that the children who participated in the Animal Fun activities showed significant improvement in both motor and social skills. Similar improvements in motor skills were replicated in an Italian study (Policastro, F. et al 2022).

Animal Fun is a universal program that aims to benefit all children, but particularly, children with disabilities within an inclusive environment.

Participants will be guided through a series of fun, interactive gross andfine motor activities to gain an understanding of how imaginary play can enhance the practice of motor skills. Participants will also learn about the rationale and research that supports Animal Fun and discuss how we involve families in partnership.

Relevance for users and families:

Animal Fun is developmentally appropriate for children aged 3-6 years. Many of the activities can be easily modified for use with older or younger children. Using imaginary play as the basis of the program makes it appealing for children but also simple for families to implement, and makes therapy FUN. From the child's perspective they are pretending to move like a particular animal, but from the therapist's perspective the child is developing core skills.

Oral Communication: Advances in Technological support 2

Use of a new technologies for upper limb assessment in children with movement disorders

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Introduction: Movement disorders (MD) in childhood include a highly heterogeneous group of conditions that lead to impairment of voluntary movement and abnormal postures. In literature, few studies focus on the use of technology for the assessment of the Upper Limbs (ULs) in children with MD; however, objective and accurate data are needed to investigate and quantify the characteristics of the MD. This study aims to evaluate and compare the different features of ULs movements in children with dystonia and chorea MD by taking advantage from devices belonging to the Virtual Reality Rehabilitation System (VRRS).

Materials and Methods: 19 children (mean age 9,73 ± 3,58 yrs) with MD participated to the study and were divided into two groups according to their prevalent MD (10 with dystonia and 9 with chorea). Children performed the standardized VRRS protocol specific for UL, by wearing a glove containing a magnetic sensor able to detect kinematics parameters related to UL movement. Trajectory, time of execution, mean velocity and jerk data were collected and analysed.

Results: Results showed significant differences among the groups regarding Velocity ($p<0.001$) and Time of Execution ($p=0.05$) parameters of the non-dominant arm. Specifically, the chorea group reports higher values in Velocity and lower in Time of Execution than the dystonia group.

Conclusions: The VRRS seems to be a useful system also for collecting quantitative data from UL, describing the movement features of children with a different type of MD and able to depict objectively the characteristics coming from the clinical evaluation.

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Relevance for users and families:

This study provides an objective and quantitative description of different features of UL movements in children with dystonia and chorea MD. Children and their families show an increasing interest in the possibility of combining standardized clinical assessment with new technological assessment measures that allow us to objectively measure the different pattern of MD. Furthermore, children are very enthusiastic doing this type of assessment, having fun thanks to the game proposals.

MOTORE: a novel technological tool for upper limb assessment in children with Unilateral Cerebral Palsy

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Introduction: Robotics offer promising solutions to rehab motor abilities in adults; however, robots could be an attractive and effective tool to evaluate and measure Upper Limb (UpL) functioning in pediatric population, as in the case of Unilateral Cerebral Palsy (UCP). The present work aims to investigate the feasibility and reliability of a planar robotic system, MOTORE, to assess the UpL motor abilities of children with UCP.

Patients and Methods: Twelve children with UCP (12.19±3.65 years) were enrolled and assessed with clinical scales (AHA, MA2, BBT).Moreover, they performed planar reaching exercises by using MOTORE both with less (LAS) and more affected side (MAS). The feasibility and reliability of the robot were assessed by correlating its output parameters (Area, Time, Velocity, Work) with the clinical scores and analyzing differences between LAS and MAS.

Results: Pearson correlation shows that the time of MAS has a significant negative correlation with AHA ($p = 0.03$, $\rho = -0.64$) and BBT ($p = 0.02$, $\rho = -0.69$) scores, and with all MA2 subscales, mainly for fluency ($p = 0.01$, $\rho = -0.74$). ANOVA analysis reports significative differences among parameters of LAS and MAS, except for time ($p_{area} = 0.040$, $p_{vel} = 0.030$, $p_{work} = 0.007$).

Conclusion: Our findings suggest that MOTORE can be used in children with UCP, providing objective and reliable measurements in line with clinical evaluation for children as well.

Relevance for users and families:

Definitely, MOTORE represents a new technological method able to support clinical assessment, ensure a playful experience, increasing motivation and engagement in children, and comply with the increasing parents interest in technologies.

Proximal proprioception in children with and without unilateral cerebral palsy, measured with state-of-the-art robotics

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Introduction: Proprioception is the ability to sense the position and movement of our body parts in space. Children with unilateral cerebral palsy (uCP) might experience proprioceptive deficits, that can impact their bimanual coordination. Robotics were suggested as a valid tool to objectify both proprioception and bimanual coordination. Hence, we investigated proximal proprioception in relation to bimanual coordination in children with uCP and typically developing children (TDC).

Patients and Methods: Forty-four children with uCP (mean age=11y8m±2y11m, 21 females, 23 right-sided uCP) and 44 age- and sex matched TDC (mean age=11y7m±2y11m, 40 right-handed) performed three tasks on the Kinarm exoskeleton robot, using elbow and shoulder movements; one proprioceptive task (contralateral position matching task) and two bimanual coordination tasks (the object-hit and ball-on-bar tasks). Proprioception was compared between groups using an ANCOVA with age as a covariate (η^2). Spearman correlation coefficients (r) were calculated between proprioception and bimanual coordination.

Results: Compared to TDC, children with uCP showed significant deficits in proprioception of the dominant (η^2=0.09-0.30; p<0.01) and non-dominant upper limb (η^2=0.12-0.22; p<0.003). Children with uCP with increased proprioceptive deficits in the non-dominant upper limb, showed worse bimanual coordination (r=0.33-0.61; p<0.03). In TDC, no significant relation between proprioception and bimanual coordination was found.

Conclusions: Children with uCP present with proprioceptive abnormalities in both upper limbs, despite their unilateral diagnosis. Those of the non-dominant upper limb are related to worse bimanual coordination. Our Results emphasize the importance of assessing proprioception in children with uCP, and the need to investigate the efficacy of proprioceptive training.

Relevance for users and families:

Children with uCP experience proprioceptive deficits in both the dominant and non-dominant arm. Furthermore, worse proprioception of the non-dominant arm seems to be related to worse bimanual function. Hence, our study Results show the importance of assessing proprioception of both arms in children with uCP. Moreover, clinicians might consider the treatment of these proprioceptive deficits, using rehabilitation programs focusing on somatosensation, as improving proprioception might enhance bimanual function in children with uCP as well.

Robotic evaluation of bimanual coordination in children with unilateral cerebral palsy with different manual abilities

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Introduction: Robotics have been proposed as a tool to measure bimanual coordination in children with unilateral cerebral palsy (uCP). However, it is unknown if they can detect coordination impairments in this population.

Methods: Three bimanual coordination tasks were performed with the Kinarm exoskeleton robot in 48 children with uCP (11y10m±2y10m, 26 males, 27 right-sided uCP, Manual Ability Classification system (MACS)-levels: I=26, II=15, III=7) and 48 age- and sex matched typically developing children (TDC, 11y10m±2y11m, 44 right-handed). In the object-hit task, participants hit balls falling from the top of the screen using virtual paddles. In the ball-on-bar task, participants moved a ball, balancing it on a bar, to a target. During the circuit task, participants performed horizontal and vertical movements with right and left hands to accurately guide a cursor through a circuit. Differences between groups and within MACS-levels were investigated using an ANCOVA with age as covariate ($\alpha<0.05$, $\eta(p)^2$).

Results: All three tasks showed worse bimanual coordination in children with uCP compared to TDC ($p\leq0.04$, $\eta(p)^2=0.05$-0.29). The ball-on-bar task ($p<0.001$, $\eta(p)^2=0.26$-0.37) and object-hit task ($p<0.01$, $\eta(p)^2=0.17$) were influenced by MACS-levels, showing that children with lower manual ability (MACS-level III), had worse bimanual coordination compared to children with MACS-level I and/or II. No differences between MACS-levels were found for the circuit task.

Conclusion: The Kinarm exoskeleton robot is a valid tool to detect bimanual coordination deficits in children with uCP, and can be used in future research to increase our understanding of how bimanual coordination deficits impact their daily life performance.

Relevance for users and families:

Currently, bimanual function is mainly objectified using clinical assessment Methods, while robotics might provide more fine-grained and quantitative information on how both hands simultaneously cooperate. Our Results demonstrated that robotics are able to show differences between TDC and children with uCP. Future research should look at the relationship between robotics, clinical tests and daily life performance to better understand the added value of robotics and the impact of bimanual coordination deficits in this population.

Individuals with dyskinetic cerebral palsy show altered upper limb kinematics in comparison with typically developing peers – a statistical parametric mapping study

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Introduction: Dyskinetic cerebral palsy (DCP) is clinically characterized by involuntary movements and abnormal postures, which aggravate with task execution. While their movement variability is recognized clinically, it remains unknown how patterns of individuals with DCP differ from typically developing (TD) peers. We explored trunk, shoulder, scapula, elbow and wrist differences between both groups.

Materials and Methods: Three-dimensional upper limb movement patterns were compared between individuals with and without DCP during three functional tasks: reach forward (RF), reach and grasp vertical (RGV) and reach sideways (RS). Angular waveforms of the upper limb joint angles were compared between groups to evaluate differences in time and/or amplitude using non-linear registration and statistical parametric mapping.

Results: Thirty-five individuals (mean age 17y4m, range 5-25y; MACS levels I(n=2); II(n=15); III(n=16); IV(n=2)) with DCP from Belgium and the Netherlands and twenty TD individuals (mean age 16y8m, range 8-25y) were evaluated. The DCP group showed decreased lateral scapula rotation in 50-100% of the reaching cycle (amplitude and timing effect) during all tasks, increased wrist and elbow flexion during RF (0-100% wrist; 60-100% elbow), RGV (0-100%) and RS (0-50% wrist; 70-100% elbow). During RGV, the DCP group showed delayed arm elevation (timing effect; 30-65%).

Conclusion: The delay in arm elevation in the DCP group during RGV may be caused by higher task difficulty, whereas the scapula rotation differences could indicate scapula instability in the DCP group. Finally, increased elbow and wrist flexion could be caused by range of motion deficits, coordination difficulties or a combination of both.

Relevance for users and families:

This is the first study exploring the movement patterns of individuals with DCP during reaching in detail, and this information on an individual level can help therapists towards adaptation of goal-directed therapy or the evaluation of intervention effects. Current analysis allows to focus more on a specific joint on the one hand or on a specific timing during the movement on the other hand.

Effectiveness of a four-week powered wheelchair training intervention in children and young people with severe cerebral palsy

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Introduction: This study aimed to investigate the effectiveness of a four-week structured powered wheelchair training program on mobility skills and mobility-related participation in children and young people with cerebral palsy (CP). A structured training program based on the Wheelchair Skills Training Program is hypothesised to improve powered wheelchair skills and subsequently positively affect daily life participation.

Patients and Methods: A one-group repeated-measures study design with a baseline, intervention and retention phase of four weeks each was used. Inclusion criteria: age 6-21-years, diagnosis of CP, and GMFCS III-V. Exclusion criteria:profound intellectual disabilities. Participants received twelve powered wheelchair training sessions of 45 minutes, 3x per week. Wheelchair skills were assessed four times using the Wheelchair Skills Test at pre-baseline, pre-intervention, post-intervention, and follow-up. Mobility-related participation was assessed with the Canadian Occupational Performance Measure (COPM). Descriptive statistics were reported using medians and interquartile ranges (IQR). To compare pre-post intervention differences, the Wilcoxon signed-rank test ($p<0.05$) and effect sizes (ES) were used.

Results: Nine participants (mean age 16y7m, range 10-20y]; all GMFCS IV) participated in the study. Statistical analysis showed improved Wheelchair Skill Test scores post-intervention (81%, [IQR 60%-88%]) compared to pre-intervention (65%, [IQR 61%-78%]; p=0.008; ES=0.57). Moreover, improvements in the COPM-performance scale (ES=0.53; p=0.012) and the COPM-satisfaction scale (ES=0.52; p=0.014) were found following the intervention.

Conclusions: Powered wheelchair mobility skills and mobility-related participation improved after a four-week wheelchair training intervention. Thereby, the Wheelchair Skills Training Program is a promising programme to improve powered wheelchair training in children and young people with CP.

Relevance for users and families:

Learning to drive a powered wheelchair proficiently can be challenging due to the severity of cerebral palsy (CP). Current evidence suggests that a structured four-week powered mobility training program can be beneficial in improving powered mobility skills in children and young people with CP. Improved powered wheelchair driving skills further impact daily life participation of children and young people, their families, and close others in a positive and meaningful way.

Mini-Symposia: Intensive interventions for children with cerebral palsy from 0 to 5 years old: perspective of implementations with & without the parents

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Objectives: This mini-symposium aims to present different modalities of training and involvement of parents in intensive training in young children and babies with cerebral palsy (CP). It will include the design and functioning of baby CIMT in Sweden (at home by parents), of a preschool and baby HABIT-ILE in Belgium (fully in a camp model), and of two mixed-model interventions of HABIT-ILE delivered by both therapists and parents either partly at home (Australia), or fully in a camp model (Bénin).

Summary: Intensive interventions effects have been demonstrated in school-age children, with a high dosage, but such a dosage might be complicated to apply in babies and very young children, especially if it requires to be parted from the parents. During this symposium, Pr. Ann-Christin Eliasson will present the baby-CIMT study, performed at home by the parents with a therapeutic supervision, Pr. Rodrigo Araneda and Astrid Carton de Tournai will explain the functioning of HABIT-ILE interventions in Belgium, in a day camp model, without the parents attending. A/Prof Leanne Sakzewski and Pr. Yannick Bleyenheuft will report the Results of mixed models with treatment delivered by parents and therapists in 2 different contexts.

Outline: The variation in possible designs for babies and young children as well as the underlying concepts will be presented and discussed, helping clinicians and scientists to delineate the applicability of each model considering the context in which they are delivered.

Relevance for users and families:

Altough the importance of early interventions is increasingly highlighted both in the literature and by the parents, there is not consensus on the various existing therapeutic models. Therefore this mini-symposium seems particularly relevant for families and users.

Mini-Symposia: Developing evidence-based consensus clinical practice guidance in cerebral visual impairment (CVI) across childhood, including definition, screening, assessment and diagnosis and classification and subtyping.

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Objectives: To report on and discuss the outputs of the EACD-funded Clinical Consensus project Europe designing international evidence-based clinical guidelines.

Summary: Cerebral visual impairment (CVI) ranging from severe loss of vision to higher-order visual perceptual disorders is a highly complex and diverse condition, with co-occurring conditions and differing severity and presentations. Significant rates are found in children with cerebral palsy and other neurodevelopmental disorders, however because of assessment challenges it is likely that a substantial subgroup remain undiagnosed or inconclusive or misdiagnosed. The CVI Consensus project Europe brings together colleagues from leading multidisciplinary clinical and research centres in developmental vision/ CVI and neurodisability/neurology and neuro-ophthalmology across Europe, USA and Australia who have undertaken a clinical consensus project commissioned and funded by EACD. This mini-symposium reports on the second-year outputs of the project team working towards novel international evidence-based consensus guidelines for improved identification and assessment and diagnosis of CVI. This project uses evidence-based systematic review and nominal group consensus methodology to reach evidence-based consensus clinical practice guidelines to support the practice of the future.

Outline of symposium

- To present the background for the CVI Consensus Europe project and project progress,
- To describe the final stages of the systematic review and output of quality appraisal,
- To discuss the outputs of the evidence-based clinical guidelines subcommittee and bringing together the evidence-based clinical and clinician generated statements,
- To share decisions on the new set of international evidence-based clinical guidelines and to consider how this can move practice forward.

Relevance for users and families:

This will provide the first international evidence-based clinical guidelines leading to greater consensus, reliability and quality in the identification and diagnosis of cerebral visual impairment conditions across the childhood lifespan. This will permit better understanding and identification of cerebral visual impairment conditions and will also provide more targeted interventions based on improved assessments and diagnostic processes. Children with cerebral visual impairment will have their needs met more successfully.

Instructional Course: Chronic pain management

Minna Ståhl[1]

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Not recived.

Relevance for users and families:

Not recived.

Mini-Symposium: "I want to see the sunshine after the rain" - reducing pain, improving life, the realities of pain management

Helen Armstrong[1], **Catriona Mckeating**[2], **Joanne Cushing**, **Riley Merrill**

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Speakers: chair Dr Helen Armstrong paediatrician, Dr Catriona McKeating paediatrician/hospice doctor Joanne Cushing mum of child with neurodisability, Riley Merrill young man with dystrophic epidermolysis bullosa.

Objectives: To share knowledge of Methods of holistic paediatric pain management.To acknowledge and share challenges plus successes in pain management and associated symptom control. To share and understand patient and family perspectives on pain management – how pain affects their lives including what helps and is valued.

Summary: Discussing pharmacological and physical interventions including Botox and splints plus medications such as Baclofen and Clonidine for symptom management. Considering the importance of symptom control of gut symptoms such as feed intolerance, vomiting and constipation. Covering the use of neuropathic agents, opioid medications and non-pharmacological Methods including distraction techniques and the role of psychological support in pain management. Raising awareness of what works and why some treatments may be more effective than others and when. Discussing what palliative care support can add topain management strategies. Sharing ofstories; allowing patient and families to discuss the effect of pain on their lives, what has and hasn't worked for them and why and how this contributes to ongoing disability and ability to participate.

Outline:

- 20 mins Dr Armstrong on Botox, Baclofen, splints etc.
- 20 mins Dr Mckeating on palliative care support and symptom control.
- 20 mins Joanne Cushing on her son and the challenges they have faced.
- 15 mins Riley Merrill on his experiences with pain.
- 15 min discussion with delegates.

Relevance for users and families:

Shared experiences of successes and challenges in pain management including the experiences of two different families living with disability associated pain

Mini-Symposium: The transition of youth with disabilities from education to the labour market

Aleksandra Tabaj[1], **Valentina Brecelj**[1], **Črtomir Bitenc**[1]

[1]URI Soča, Ljubljana, Slovenia

Introduction: While the transition from education to employment is a demanding process for every young person, so much more is true for youth with disabilities (YwD). Successful transition requires support that starts during schooling and continues in the transition to employment until stability in the job. The aim of the Slovenian project "Transition of YwD" (ESF founded, duration 2018–2022) was to create a support framework model for better social inclusion and employment solutions that prevent long-term unemployment.

Patients and Methods: participants were YwD (2.100), aged from 12 to 28. The analysis was made on the data provided by vocational rehabilitation providers (VRP). Five questionnaires were created (for YwD, their parents, school counsellors, employers, and VRP professionals). All the descriptive statistics were calculated in MS Excel 2021.

Results: Based on a new model, expected outcomes were employment, education, and unemployment – the majority of YwD decided to continue with education.

Conclusion: Many benefits were discovered during the project: the YwD highlighted received psychosocial support, guidance and information. Whereas the improved motivation, self-confidence, and empowerment of YwD were highlighted as particularly positive by their parents as well as by employers. Counsellors, on the other hand, reported being especially satisfied with VRP professionals, their communication, attitude and flexibility.

Relevance for users and families:

With the project, awareness about possible support for YwD was spread not only among them and their parents but also among the schools and employers – two sectors where the lack of specific knowledge of support was observed and reported.

Instructional Course: Better future for assessing verbal comprehension with the Computer-Based instrument for Low motor Language Testing (C-BiLLT), in unintelligible or non-speaking children with (severe) motor impairments

Nika Jelenc[1], **Johanna Geytenbeek**[2], **Kristine Stadskleiv**[3]

[1]University Rehabilitation Institute Republic Of Slovenia, Ljubljana, Slovenia, [2]Amsterdam UMC, Amsterdam, Netherlands, [3]Oslo University Hospital, Oslo, Norway

Objective: To realize the implementation of a tailored language assessment in Europe for children with complex communication needs (CCN). Learning objectives for the course are (1) to gain awareness of the C-BiLLT currently used in different European countries, (2) recommendations for implementation in other languages, (3) preliminary Results of the Slovenian version of the C-BiLLT, (4) awareness of the role of reliable and valid language comprehension measures as being indicative for provision of alternative and augmentative communication.

Target audience: Speech and language therapists, psychologist, pediatric neurologists, pediatricians and other professionals who work with children/young adults with CNN.

Summary: The ”Computer-Based instrument for Low motor Language Testing” is a norm-based test, available for use in the Netherlands since 2015. The C-BiLLT (1) requires a minimum of motor action to respond to test items, (2) items pertain to spoken language comprehension abilities on a word and sentence level, and (3) items refer to the experiential environment of the child with (severe) impaired mobility. The child can provide responses using a variety of alternative access Methods (e.g., scanning, touchscreen, gaze or eye-gaze).

Outline of the course:

- The tailored use, reliability, different access Methods, challenges, and success of the cultural and linguistic adaptations of the translated C-BiLLT versions,
- Experience with the use and implementation of the C-BiLLT in Norway,
- Preliminary Results of the Slovenian version of the C-BiLLT.
- “Barriers and Facilitators” survey among the users of the C-BiLLT in Norway, Belgium & The Netherlands.

Relevance for users and families:

Better understanding of verbal language comprehension skills in children with complex communication.

Instructional Course: Binocular and ocular functional diagnostics made simple in children with disabilities for a multi disciplinary team of medical professionals involved in treatment of children with disabilities.

Sunita Agarwal[1], **Aditya Goyal**, **Anjan Bhattacharya**

[1]Nabajatak Child Development Centre, Kolkata, India

Objective:

- Understanding the importance of ocular functional and binocular assessment.
- Ocular functional and binocular assessment simplified with a software application.

Learning objectives of the course:

- Understand the importance of visually guided behaviour in children with disbilities.
- Be able to perform binocular and functional ocular diagnostics using a software application.
- Analysis and interpretation of the diagnostic data.
- Better informed co management of children with disabilities.

Target audience: All medical and allied professionals involved in treating children with multiple disabilities.

Summary: This course will make the medical and allied healthcare professionals understand the importance of eyes and ocular functions in the treatment of children with disabilities. The professionals will be able to diagnose, analyse and manage/ comanage ocular/ binocular functions using easy to use tools.

Outline of the course:

- Emphasising the role played by the eyes in behaviour of a child.
- Description of the importance of appropriate assessment of ocular and binocular functions.
- Demonstration of assessment using easy to understand and use software application.
- Analysis of the data and management/ comanagement of the cases.

Relevance for users and families:

This course will improve the understanding of the participants about binocular and functional ocular assessment and its relevance in achieving better Results with other therapies.

Instructional Course: Participatory research partnership in rehabilitation – a model for a meaningful collaboration process

Salla Sipari[1]

[1]Helsinki Metropolia University Of Applied Sciences, Helsinki, Finland

Objective: Collaboration that engages diverse stakeholders to actively participate in the rehabilitation research process is becoming a crucially important approach when promoting well-being in everyday life. We will introduce the Participatory Research Partnership (PaRe) model (Sipari et al. 2022). The model describes collaboration between family members, researchers, professionals and stakeholders. The model consists of five phases: 1) Starting a research partnership, 2) Building a research group, 3) Reciprocal joint planning of research, 4) Producing new research information together and 5) Utilizing research information in everyday life. The model includes examples and templates including developmental and ethical evaluation. The PaRe-model was co-developed including literature review, workshops and interviews (over 100 participants: experts by experience, professionals, researchers). The model was tested, evaluated and further developed in a development training process with 50 experts in rehabilitation.

Learning objectives of the course: In the workshop, we will familiarize to the PaRe-model and co-create a view for utilizing the model.

Target audience: This course is intended for everyone who is interested in collaborative research.

Summary: In this instructional course participants will learn concrete steps and tools to build participatory research partnership. The model can be applied to various scientific approaches and Methods in research networks.

Outline of the course: First, the PaRe-model is briefly introduced, and materials shared for participants. Then the presenters facilitate to try out the model and its templates in small groups. Results of the group work are summarized together. Finally, a discussion of the implementation of the model is conducted.

Relevance for users and families:

The model aims at building a conscious partnership between different parties:

researchers, rehabilitators and their families. The model enables equal and reciprocal participation and promotes partnership-based research process with especial focus on familyengagement and meaningful collaboration. The PaRe-model can be applied in practice in different context to develope child and youth rehabilitation. The modelimproves the relevance and accessibility of research data. The co-produced new knowledge is meaningful and usable in everyday life.

Instructional Course: Focusing on Strengths and Functional Needs: Using About My Child and Related Tools to Facilitate Access to Services

Marilyn Wright[1], **Peter Rosenbaum**[1], Rachel Teplicky[1]

[1]CanChild, McMaster University, Hamilton, Canada

Objective: This course will explore the identification of child/family strengths, needs, and contextual factors to facilitate access to timely, goal and participation-focused, culturally sensitive, and equitable child development services.

Learning Objectives: About My Child and the Access and Equity Inquiry will be introduced as tools to conduct exploratory conversations with families. We will:

- Describe an F-words focused strengths- and functional-needs based approach to service access and delivery
- Introduce About My Child (and versions for babies and youth) and the Access and Equity Inquiry
- Explore case scenarios to illustrate how the tools can be used to support clinical decision making and determine need for developmental services
- Consider aspects of cultural safety, sensitive inquiry, and use of data related to these tools

Target Audience: Service providers, families, physicians, researchers

Summary: About My Child, About My Baby/Toddler, and About Me are caregiver or youth reports of strengths, interests, concerns about functioning, and their impact on participation in everyday activities. The Access and Equity Inquiry is a conversation guide to explore personal and environmental factors that can impact a family's ability to take part in services. These tools are not specific to diagnoses and assist in determining health service priorities. They engage and empower families to reflect on their strengths and identify their concerns and priorities for services. Using these tools facilitates the provision of tailored, family-centred, and needs-based services.

Outline of the course:

- Strengths and functional-needs based services
- Introduction to tools
- Interactive case examples
- Discussion

Relevance for users and families:

About My Child and the Access and Equity Inquiry can be used to guide conversations with families. The tools engage and empower families to reflect on their strengths and identify their concerns and priorities for services. Using these tools facilitates the provision of tailored, family-centred, and needs-based services.

POSTER PRESENTATIONS

A model for achieving multi-disciplinary standards of care for neuromuscular disorders

Denise McDonald[1], Susan Byrne, Terence Prendiville, Fiona Ringholz, Ciara McDonnell, Jim Kennedy, Sinead Brennan, Andrea Tobin, Niamh O' Connor, Aoife Hyland, Laura Gallagher

[1]Children's Health Ireland At Tallaght, Dublin, Ireland

Neuromuscular disorders are collectively rare but demand a high level of multidisciplinary specialist support to meet published standards of care. The burden of attending hospital appointments on children and families is high, especially where twice yearly multi-specialist reviews are mandated.

In Children's Health Ireland (CHI) at Tallaght, 69 children and young people with neuromuscular disorders attend the service. The commonest conditions among this cohort are Duchenne muscular dystrophy and spinal muscular atrophy. In order to reduce family burden and optimise liaison between professionals, the clinic operates as a multi-disciplinary medical and therapy 'one-stop-shop'. Attending clinicians include neurology/neurodisability, cardiology, respiratory, endocrinology (bone health), orthopaedics, nursing, physiotherapy, occupational therapy and psychology. Each child and family is assigned a room, and clinicians rotate through to complete individual consultations. A team meeting after each clinic optimises collective decision making.

Families experience a long clinic day but appreciate this is twice yearly, compared to multiple individual appointments throughout the year. They are positive about the privacy offered in an assigned clinic room, while knowing there are other families present should they wish to engage in peer support. Clinicians value the ability to liaise directly about the care of a complex cohort of children and young people.

This model has been presented in the National business case for a paediatric neuromuscular service, which will provide a standardised service for the neuromuscular population across the Republic of Ireland. This proposal includes the case for expanded resources, including speech and language therapy, social work and service coordinator.

Relevance for users and families:

the clinic described reduces the number of clinic attendances throughout the year, thereby reducing travel and time lost to school, work and home life. It optimises communication between the multiple professionals involved in their child's care. It has a clear focus on meeting clinical standards of care.

Impact of a family-centered early intervention program ´Good Start´ on parents of children with Cerebral Palsy

Camilla Marie Larsen[1,2], Danielle Louise Nørager Johansen[1], Thomas Skovgaard[1], Lars Breum Christiansen[1], Charlotte Boslev Præst[1]

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Introduction: This study evaluated the impact on well-being, self-efficacy and empowerment among parents of children with cerebral palsy who received education and guidance as part of an intensive 4-day family-centered early intervention program ´Good Start´.

Methods: This single arm pre-post intervention study compared changes in outcomes from baseline (pre-program) to 3 weeks and 6-month post program participation among 38 parents. Outcome measures: Short version of the Warwick-Edinburgh Mental Well-being Scale (SWEMWBS), Family subscale (FS) from Family Empowerment Scale, Efficacy subscale (ES) from Parental Sense of Competence Scale.

Results: Of the 38 parents (50% women), most were part-time/full-time employed (84%). 68% of the children were between 1-2 years old. An unadjusted mixed-linear-model analysis showed significant effect of time for two outcome measures. Mean change from baseline in the SWEMWBS was after 3 weeks; 1.5 (95% CI: 0.7; 2.4), lasting up to 6 months; 1.3 (95% CI: 0.4; 2.2), representing improved well-being. The mean change for the SE score was 0.8 (95% CI: -0.3; 2.0) after 3 weeks and; 1.5 (95% CI: 0.3; 2.7) after 6-month, representing improved parental self-efficacy over time. No change was observed in FS (mean 3.9 at all time-points).

Conclusion: A family-centered early intervention program ´Good Start´ for parents of children with cerebral palsy demonstrated positive change in parental well-being and self-efficacy. Overall, family empowerment ratings were relatively high indicating good family resources. Studies with larger samples are needed to confirm the findings of this study.

Relevance for users and families:

Family-centered early intervention can improve parental well-being, and self-efficacy; thereby positively affect the support for children with cerebral palsy.

Improving Documentation for Children with Complex Needs And Severe Neurological Impairment In Children's Health Ireland: A Quality Improvement Project

Dearbhla Hillick[1], Siobhan McCormack[1,2], Maeve Ledden[1], Zaineb Elbishari[1], Stephanie Kelly[1], **Joanne Balfe**[1,3]

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Introduction: Children with Severe Neurological Impairment (SNI) have high healthcare needs, attend multiple specialities and have frequent interactions with services. When children with SNI are admitted to hospital, this often occurs out-of-hours and involves staff that are unfamiliar with them. Comprehensive summaries are often non-existent, medication records may not be up-to-date and locating all the relevant information from multiple sources is time constraining and difficult. We aim to improve the care provided to children with SNI and their families by focusing on reducing: 1.The burden on clinicians to locate key information and 2. The need for parents to repeat background details.

Methods: Our multidisciplinary team completed the Lean Six Sigma Green Belt Certification. Using a data collection template of what was deemed critical-to-quality(CTQ) information, time taken to capture background information and the number of absent details were measured on the records of a sample of children with SNI.

Results: Seven patient records were reviewed. The average time taken to find background information was 22 minutes. 62% of CTQ background information was complete. Two new proforma documents were developed with a phased roll out. Pilot of the new summary proforma led to a reduction from 22 minutes to 3 minutes for the time taken to acquire the background information, an 86% reduction.

Conclusion: The use of a complex care summary will greatly improve the care provided. The family and chart will have a copy, along with an electronic copy on the computer system with ultimate integration to the electronic health record.

Relevance for users and families:

This document will make a real difference to families by removing the need for parents to recall and repeat background history. This also will allow more clinician time to be spent on direct patient care.

What means timely intervention in orphan disease?

Tamara Crnković[1], Sanja Jurišić, Svetislav Polovina, Milena Stojčević Polovina

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Orphan diseases in childhood usually have wide spectrum of symptoms. That means that early intervention system needs a huge number of experts from different areas of medicine and rehabilitation. Example is Cockayne syndrome (CS), a rare disease characterized by a variety of clinical features including dwarfism, severe neurological manifestations which includes learning problems and motor delays, vision problems, hearing loss, feeding difficulties, bone abnormalities etc. Questionnaire carried out with the family with two girls with this syndrome shows that over 20 different medicine doctors and therapists seen girls until they were five years old. That number implicates that there is no system support for children with orphan disease and their families. There is no coordination between service providers so it happens that therapists of the same profile do different things with the same child and the programs and services are not coordinated. The result is girls have not reached their maximum in motor and communication development because parents didn't have continuous support. The goal is to establish system with the main expert, service coordinator, who is competent to say when is the right moment for new intervention and who is available to family.

Relevance for users and families:

Need for better organization of system for better support to parents and families. It will help children do reach better Results and more independent life.

Identification of movement disorders in cerebral palsy: A European-wide survey of clinicians

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Introduction: Identifying movement disorders in cerebral palsy (CP) mainly determines treatment options. However, available Methods for the identification of movement disorders are often not used in clinical practice. The objective of this study was to examine the difficulties clinicians experience in identifying and discriminating movement disorders in children with CP.

Materials and Methods: A cross-sectional voluntary response survey was developed via Qualtrics. Survey questions were related to the clinical background of the respondents, their knowledge, beliefs and used Methods to identify movement disorders in CP. The survey was sent to clinicians in Europe via the European Dyskinetic CP Network. Descriptive statistics and frequency analysis were used to present the Results.

Results: The survey was answered by 87 clinicians, with 70 completing all questions. Respondents were physiotherapists (n=42), paediatric neurologists (n=22), paediatricians (n=7), occupational therapists or physiatrists (n=5), and orthopaedic surgeons (n=2). Most respondents were from Central/Eastern Europe (n=28), followed by Northern, Western and Southern Europe (respectively n=22;n=21;n=9). Half of the respondents had more than 15 years of experience and only 14 respondents had five years or less of experience. Main reasons for difficulties in discriminating movement disorders were lack of experience and education in using measurement tools. Important barriers for using measurement tools were lack of time, test equipment and education.

Conclusion: Current study defined the difficulties that clinicians experience in identifying and discriminating movement disorders in CP. Lack of education should be targeted during the clinicians' education, whereas lack of experience could be countered by a more multi-disciplinary approach.

Relevance for users and families:

Insights in the reasons complicating identification of movement disorders allows us to adapt educational and clinical approaches to obtain more effective education tools and more confident clinicians. This is important for patients because early identification of the correct movement disorder can facilitate early and specialized intervention to improve quality of live.

Cognitive assessment practices for children with cerebral palsy in Norway

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[1]University Of Oslo, Oslo, Norway, [2]Oslo University Hospital, Oslo, Norway

Introduction: The CPCog is a protocol for systematic assessment of cognition in children with cerebral palsy (CP). Following the Introduction of the CPCog in Norway in 2013, efforts have been undertaken to 1) increase the number of children assessed, 2) investigate if there are systematic differences in whom are offered assessments, and 3) investigate parental perceptions of cognitive assessments.

Patients and Methods: Participants are psychologists at the paediatric habilitation services, 1532 children with CP, born 2002–2014, and parents of 181 children with CP. The children should have all been offered assessment of cognition, as detailed in the CPCog.

Results: Inviting all Norwegian paediatric habilitation services to a quality improvement project increased the percentage of children assessed from 34 to 62%. Children not assessed were either just clinically evaluated (n=304 of 1532), considered not assessable (n=106) or no data on cognition was reported (n=150). Among 972 children assessed, IQ was available for 451. Children with severe speech and fine motor impairments or with vision impairments were least likely to be assessed. Among parents whose children were assessed, only 6% did not agree with the findings, comprised mainly of parents of children with severe motor impairments.

Conclusions: Assessments should also be offered children with severe speech and motor impairments and be conducted so that parents may place confidence in the findings.

Relevance for users and families:

Cognitive assessments contribute towards detecting need for follow-up of children with CP and most parents (66%) express that assessments play a positive role in that regard.

Perceptual disorder signs on movement in children with cerebral palsy in a Swedish context: an observational study

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Introduction: Identifying perceptual disturbances on movement is important for motor function prognosis and for planning intervention aiming to enhance mobility in children with cerebral palsy (CP). The aim was to assess recognition of six clinical signs of perceptual disorders with influence on movement in children with bilateral CP.

Patients and Methods: 56 videos of 19 children (12 boys, 1-18 years of age) with bilateral CP (GMFCS I-V) showing six signs of perceptual disorders were included. Inter-rater reliability was assessed between 3 experienced raters. Criterion validity was evaluated by analyzing agreement between these raters individually and an expert opinion (gold standard). In addition, inter-rater reliability in recognizing a subset of signs in-between 47 clinicians were evaluated after a one-day education, as a measure of clinical applicability.

Results: Moderate to almost perfect inter-rater reliability (kappa 0.54-0.81) in between three experienced raters and criterion validity (0.54-0.87) were found when evaluating startle reaction (SR), upper limbs in startle position (SP), adverted eye gaze (AEG) and eye blinking (EB). These signs could also be recognized with at least moderate reliability (0.56-0.88) by clinicians. Grimacing (G) and posture freezing (PF), showed less reliability (0.22-0.35) and validity (0.09-0.50) assessed by both experienced raters and clinicians.

Conclusion: The study supports that the clinical signs of perceptual disorder, SR, SP, AEG and EB, can be reliably recognized in children with CP in a Swedish context both by experienced raters and clinicians in the field. However, G and PF, showed less reliable and valid Results and more studies are needed.

Relevance for users and families:

Perception as incorporating and interpreting sensory information to meaningful activities is of importance for functioning of a child. Perceptual function most likely influences movement and posture in children with CP and should always be considered when discussing prognosis and intervention. Development of a tool that evaluates movement perception is of highly clinical relevance for children with bilateral spastic CP.

Implementation of the state-wide Queensland Early Detection Network (QEDIN-CP) – prediction of outcomes for infants at risk of adverse neurodevelopmental outcomes

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Introduction: The QEDIN-CP network supports implementation of the CP early detection guidelines; providing training, support for early screening, to fast-track infants to early intervention. This study evaluates the relationship between screening and outcomes in a prospective cohort of infants at risk of CP or adverse neurodevelopmental outcomes (NDO).

Patients and Methods: 574 clinicians, across 18 sites, were trained in (i) General Movements Assessment (GMA; n=246) (ii) Hammersmith Infant Neurological Examination (HINE; n=328), over a 5-year period. Infants were screened at 0-12 months corrected age (CA) using GMA, Motor Optimality Score (MOS) and HINE with outcomes at 24 months CA on Ages and Stages Questionnaire (ASQ-3) and/or paediatrician diagnosis, classified as i. typically developing, ii. CP or iii. adverse NDO (<2SD on ASQ-3).

Results: 770 infants were referred with 637(83%) consented, 439(69%) were born preterm (mean GA= 33 wks) with 116(18%) extreme preterm. Of these 463(73%) completed GMA, (n=184, 40% writhing, n=432, 93% fidgety), with 308(71.3%) normal, 18(4.2%) abnormal and 106(24.5%) absent fidgety. At 3-12 months 290(45%) infants completed HINE assessments (mean=57.5, SD=12.5). 95(15%) infants received a diagnosis of CP at any age. Of 200(87.7%) infants with completed outcomes, a further 37(18%) were “high risk of CP” at 24 months. 118(19%) infants were fast-tracked to early intervention studies.

Conclusion: Large scale implementation of the CP early detection guidelines is feasible utilising a collaborative state-wide approach and clinical support network providing training, second opinions and calibration sessions. Early identification of high-risk infants promotes early access to CP specific supports and services.

Relevance for users and families:

Families with infants at high chance of a later diagnosis of Cerebral Palsy and/or an adverse Neurodevelopmental outcomes can receive very early surveillance using evidence based tools. A state-wide early surveillance program utilises evidence based tools for early accurate recognition of infants at high chance of Cerebral palsy and other adverse neurodevelopmental disability (ASD,DD). Early surveillance provided by trained clinicians utilising Baby Movement App enables access to surveillance in both metropolitan, region and remote settings.

Which cognitive evaluation instrument to use for children with Cerebral Palsy?

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Introduction: The evaluation of the cognitive functioning of children with a standardized intelligence scale, requires both verbal and motor responses. Children with Cerebral Palsy (CP) are often impacted by a motor impairment, a speech deficit or a visual impairment. The evaluation of the cognitive abilities of children with CP with a standardized instrument often leads to underestimation of their possibilities. This abstract aims to explore the existing test batteries in a search for the most appropriate diagnostic instrument to measure the IQ of children with CP, taking into account their impairments.

Methods: A literature review was done. A qualitative questionnaire was sent by e-mail to all 8 CP Reference Centers in Belgium.

Results: 5 centers participated. Literature suggests the Raven's Coloured Progressive Matrices as a reliable test to evaluate the visuoperceptual functioning and memory of children with a motor and/or speech disorder. However, lacking updated standardization, a limited number of items and the absence of a verbal index, Results in a shortage of information to develop a holistic rehabilitation plan to optimize daily functioning. Experts prefer the selection of subtests of different test batteries according to the functional profile of the child with CP. Most common used batteries are BSID-III, WPPSI-IV, WISC-V and SON-R 2-8.

Conclusion: Currently, there is no standardized instrument evaluating the cognitive profile of children with CP, taking into account their impairments. Experts confirm the need for further research and the development of more appropriate test batteries or adaptations in existing test batteries.

Relevance for users and families:

Relevance for users and families: To develop a holistic rehabilitation plan to improve daily activities on all domains for children with CP, a reliable evaluation of the cognitive functioning with a standardized instrument, is needed.

Prediction of Neuromotor Outcome in Infants Born Preterm at 6-8 Years of Age Neurological Examinations

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Introduction: To study the prognostic value of neurological examinations at term equivalent age (TEA) at 6-8 years of corrected age for long-term neuro-motor outcome in infants born very preterm.

Patients and Methods: A total of 50 infants born very preterm were included. Neurologic examination was done at TEA (6-8 years). The Neurological, Sensory, Motor, Developmental Assessment (NSMDA) was performed at 1, 4, 8, 12 months of corrected age. Academic achievement and demographic information were recorded.

Results: Of all children (mean birthweight 1377 g [min-max=720-2980]; gestational age 29.8 weeks [min-max=24-36], duration of staying in intensive care unit 42.02 days [min-max=3-135]). 41 had normal neurological examination by the pediatric neurologist, 38 had good academic achievement, and 45 had normal development outcomes scores as per NSMDA. While there was a statistically significant relationship between academic achievement and neurological examination (r=0.590; p=0.000), no significant correlation was found between NSMDA and neurological examination (r=0.244; p=0.088).

Conclusion: Although the NSMDA and neurological examination Results were independently similar (normal development; 45 vs 41) there was no correlation between them. Neurological examination at TEA predict long-term neuro-motor outcome in infants born preterm. Especially, normal findings strongly predict normal outcome. Combinations of neurological examinations and imaging techniques are plausible in improving the prediction for abnormal outcome. However, long-term follow-up data considering these Methods are still needed.

Relevance for users and families:

Neurological examinations of neonates and infants correlate with long-term neuro-motor outcome. Small for gestational age infants have similar developmental outcomes compared to other infants born preterm in this study population. Long-term outcome assessments will follow from parents and health proficiencies who responsible for the diagnosis and rehabilitation.

Stretch hyperreflexia during gait in children with cerebral palsy using dynamic ultrasound imaging

Babette Mooijekind[1,2,3], Eline Flux[1,2], Lynn Bar-On[3], Edwin van Asseldonk[4], Annemieke Buizer[1,2,5], Marjolein van der Krogt[1,2]

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Introduction: Children with spastic cerebral palsy (SCP) are presumed to experience stretch hyperreflexia (i.e. spasticity) during walking. Thus far, this has been assessed by analyzing modeled musculotendon stretch and resulting electromyography (EMG) activity. We hypothesized that children with SCP display hyperreflexia during walking compared to typically developing (TD) children, which is more pronounced when measuring fascicle- rather than modeled musculotendon- stretch.

Patients and Methods: 3D-gait analysis including EMG was performed on fourteen children with SCP and fifteen TD children. Medial gastrocnemius fascicle stretch was assessed with dynamic ultrasound imaging. Musculotendon stretch was modeled using OpenSim. Hyperreflexia, defined as visually determined increased EMG shortly preceded by a peak in stretch, was identified during late swing and early stance. Ratio RMS EMG/peak stretch was calculated and compared between SCP and TD using independent t-tests.

Results: 62.5% of children with SCP showed fascicle stretch peaks preceding increased EMG in late swing, compared to 50% for musculotendon stretch. For early stance, this was 53.8% and 46.2% respectively. TD showed no increased EMG. EMG/stretch ratios were larger for SCP then TD, for both fascicle (91.5±57.4 vs. 28.6±14.5 for swing and 362.0±329.0 vs 96.7±135.6 for early stance, $p<0.001$) and musculotendon stretch (50.9±26.6 vs 15.0±8.4 for swing and 120.9±52.1 vs 29.2±16.8 for early stance, $p<0.001$).

Conclusion: Identifying more hyperreflexia by studying fascicle- rather than musculotendon- stretch, provides additional evidence of hyperreflexia during gait in SCP. However, increased activity was not always preceded by stretch. Therefore, other tissue dynamics or mechanisms might explain the increased activity.

Relevance for users and families:

This study confirms that children with SCP experience spasticity during walking. This seems only slightly more related to fascicle stretch, suggesting contribution of other tissue dynamics. More knowledge on the underlying mechanisms can help direct treatment.

Genetic Diagnosis and Prognostic Assessment of Children with Autism Spectrum Disorder of Kolkata Developmental Model

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Introduction: Research shows that Autism Spectrum Disorder (ASD) is highly genetic and majorly heterogeneous in nature. Our two year long study conducted at our Child Development Centre on the Indian population shows the involvement of a spectrum of multi genes. Our study depicts the need for precise genetic counseling and the potential outcomes of genetic testing for etiological benefits to the patients and families with ASD children.

Patients and Methods: At our CDC from 2020 to 2022, a total number of 98 children with diagnosed ASD have undergone genetic counseling. As per the recommendation by American Association of Pediatrics (AAP), a total number of 43 patients with diagnosed Autism have undergone genetic testing including whole exome sequencing, chromosomal microarray and Fragile X testing. The tests were chosen on the basis of clinical and family history of each patient.

Results: Out of the 43 children 4.6% of patients have been detected with chromosomal microdeletion and duplication; 37% patients have been detected with single nucleotide variants in 20 different genes following autosomal dominant inheritance and 7 genes following X-linked inheritance. The Remaining 58% children were detected with no significant variant or chromosomal microdeletion/duplication.

Conclusion: This study discusses the different types of genetic findings through the series of cases to understand the etiological and prognostic benefit of the testing, need for further familial targeted testing and genetic counseling by genotype-phenotype correlation, assessing the family histories, variant specific analysis and post therapeutic disease prognosis of the children with genetic variants.

Relevance for users and families:

Understanding the population specific genetic modifiers helps to understand the disease etiology and in early intervention. It also helps to estimate the disease prognosis and possible therapeutic intervention. Genetic counseling helps the families to find the diagnostic closure and to plan their future family.

Recognising collagenopathy disorders in neuropaediatrics: a case series

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Introduction:Collagenopathies are a heterozygous group of inherited conditions caused by genetic defects of collagen formation. They affect multiple organ systems including musculoskeletal, vascular, and neurological. Due to their ubiquitous nature, clinicians must have a high level of suspicion to inform further diagnostic testing and optimise management.

Case Series:Four children presenting to paediatric clinics

Case 1: An eighteen-month-old boy with hypotonia and gross motor delay. He had several dysmorphic features noted and significant joint hypermobility. A diagnosis of vascular Ehlers-Danlos Syndrome(EDS) with a COL3A1 pathogenic variant confirmed.

Case 2: A two-year-old girl with gross motor delay, headaches and joint hypermobility. She had clinical features of classical EDS which was confirmed by genetic testing demonstrating a COL5A1 novel mutation.

Case 3: A five-month-old girl with a right-sided hemiplegia, genetic testing revealed a COL4A2 pathogenic variant which led to identifying multiple family members affected with cerebral vasculopathy.

Case 4: A five-year-old boy who attended the neurology clinic with challenging behavior (subsequently found to be due to fatigue and joint pain) with a background of sensorineural hearing loss and high myopia. Examination revealed joint hypermobility. Diagnostic investigations and a diagnosis of COL2A1 Stickler syndrome was made.

Discussion:Collagenopathy disorders can present to any paediatric clinic. Joint hypermobility is an important clue. All four cases highlight the importance of a thorough history and clinical examination to inform diagnostics and support management. Accurate diagnosis is important for management and counselling, there is a major treatment gap and need, as there are no molecular-based precision therapies available for the cases described above.

Relevance for users and families:

Our case series demonstrates real life stories of families being diagnosed with a rare collagenopathy disorder. As mentioned, the ubiquitous nature of collagenopathy disorders means that often these children have presented to multiple clinics with multiple issues prior to get an overarching diagnosis. We seek to highlight the importance of thorough history and clinical examination in expediting diagnostics. The importance of getting a timely diagnosis for families is essential in guiding future care.

Exploring neurodevelopmental phenotypes in children with molecularly proven PAX6 mutation Aniridia – a preliminary analysis.

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Introduction: Children with visual impairment are at greater risk of neurodevelopmental disorders, such as autism, than the general population . Heterogeneity in the presentations of autism reflects the complexity of the aetiological role of genetic and epigenetic factors . PAX6 haploinsufficiency can lead to abnormal brain development. We explored parent reported behaviours in a cohort of children with Aniridia and molecularly proven PAX6 gene mutations.

Methods: Social Responsiveness Questionnaires - 2nd Edition (SRS-2) and Goodman's Strengths and Difficulties Questionnaires (SDQs) were completed by parents of 12 children, 8 males and 4 females, mean age 10.08 years (SD 3.65; range 4.5-15.5 years). Children with additional genetic mutations were excluded. Visual acuity was recorded at closest clinical visit to questionnaire completion. Results of questionnaires were compared to population data.

Results:

- Frameshift, nonsense missense and intronic PAX6 variants were represented
- 66.5% of parents reported statistically significantly high mean total T-scores on the SRS-2 warranting further clinical assessment for autism (p=<0.001). This was similarly reported across all subscales of the SRS -2, with the most severe symptoms (33.3%) reported in children with the highest scores in Restricted, Repetitive Behaviours.
- Statistically significant differences were found in the mean total difficulties score on the SDQ's for internalising behaviours (difficult peer relationships and prosocial behaviours)

Conclusions: Children with molecularly proven PAX6 gene mutations appear to be at increased risk of autism. Early referral to Paediatricians is recommended for assessment and evaluation of reported behavioural difficulties.

Relevance for users and families:

Relevant to children and families with this rare eye condition as it will enable earlier recognition and management of neurodevelopmental phenotypes. The advantage of highlighting the phenotype will alert Ophthalmology colleagues to the importance of involving Paediatricians in the care of children with the condition for earlier identification and management, in particular Autism and ADHD management and associated other mental health co- morbidities

Hip joints in spinal muscular atrophy - literature review and personal experience

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Introduction: So far, there are no reports in the literature concerning instability of the hip joints in people treated with spinal muscular atrophy (SMA). Due to the change in life prospects of these patients, this problem becomes important in the field of epidemiology, diagnosis, prevention and treatment.

Patients and Methods: 18 children (36 hips) with SMA type I, II and III were observed. All patients underwent a clinical examination of the lower limbs, an x-ray of the hip joints in the AP projection, and the presence or absence of pain in the hip joints was noted. In addition, a literature review was performed.

Results: Dislocation or subluxation of the hip joints occurred in 15 patients (28 hip joints). Contractures in the hip or knee joints were presented by 12 patients, and pain in the hip joints was reported by 3 patients.

Conclusions: Dislocation or subluxation of the hip joints is very common in patients with spinal muscular atrophy. The emergence of the possibility of therapy, both in the form of gene therapy and pharmacotherapy, leads to the stabilization of the disease, the improvement of the motor skills of the treated patients or stopping the development of the disease in patients who started treatment in the presymptomathic period. Due to the new perspectives of patients with SMA, there is a need to create an algorithm for diagnostic and therapeutic procedures for neurogenic hip joints in these patients.

Relevance for users and families:

Expanding knowledge and better understanding of the natural course of the disease and treatment perspectives by patients and their family members

Speech therapy needs in a French cohort of children with arthrogryposis multiplex congenita.

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Introduction: Arthrogryposis Multiplex Congenita (AMC) is the result of decreased fetal movement. Despite a major impact on gross motor skills, orofacial or language impairments have not been evaluated on large pediatric cohorts.

Patients and Methods: The objective of our work was to highlight the frequency of speech therapy needs in children with AMC from our Reference Center for AMC at the University Hospital Grenoble-Alpes. We retrospectively included a cohort of 137 pediatric patients from September 2007 until November 2020 and searched for speech therapy needs in medical charts. We then included prospectively 17 patients over the period from November 2020 to March 2021 in whom we assessed systematically speech therapy needs.

Results: We found that the frequency of orofacial and language impairments in our total cohort was 31.4%. The systematic evaluation showed a higher frequency, in particular explained by the overrepresentation of an etiological group with associated disorders (3rd etiological group). In contrast, patients with Amyoplasia had a lower frequency of need for speech therapy. These Results support our hypothesis that the frequency of the need for speech therapy is strongly influenced by the etiology of AMC. The most frequent oro-myo-functional anomalies affected functions such as sucking, swallowing, chewing, articulation and language.

Conclusion: Our study highlights the interest of a systematic speech therapy evaluation within the framework of AMC, and particularly for the etiologies of group 3.

Relevance for users and families:

Our Results may help to better tailor speech therapy needs to pediatric patients with AMC.

Neuro-imaging characteristics of sensory impairment in cerebral palsy; a systematic review

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Introduction: Tactile deficits account for approximately 30% of the variance in upper-limb motor function in children with cerebral palsy (CP). The underlying pathophysiology of sensory compensation mechanisms is still poorly understood. We aim to identify and examine neural reorganization of the sensory network in patients with CP.

Methods: Systematic review concerning sensory connectivity in relation to sensory outcome in patients with CP< 30 years of age.

Results: Next to MRI, five additional neuro-imaging/neurophysiological techniques were used. Sensory function was assessed using a combination of thirteen sensory assessments, i.e. tests, protocols as well as evaluation criteria.

Children with periventricular leucomalacia (PVL) lesions have significantly better hand function and sensation scores than children with cortical-subcortical lesions. Interhemispheric reorganization of the sensory system after early brain lesions is rare and, when it occurs, poorly effective. Ipsilesional reorganization of the S1 (primary somatosensory cortex) area appears to be the primary compensation mechanism. Fractional anisotropy (FA) is lower, and mean (MD), radial, and axial diffusivities are higher in the lesioned hemisphere and associated with poorer tactile function.

Conclusion: Because of the large variability in neuroimaging and sensory assessment Methods, it is difficult to draw definite inferences on the relationship between the reorganization of the sensory network and sensory function in children with CP. In general, sensory function seems to be worse in cortical as opposed to PVL type lesions.

Relevance for users and families:

Understanding the pathophysiology of this reorganization process and relating this information to sensory and functional outcomes, might ultimately lead to different approaches and rehabilitation strategies.

Gait abnormalities in FOXP1-patients, a case series report

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Introduction: FOXP-1 syndrome is a neurodevelopmental disorder caused by mutations or deletions in the forkhead box protein 1 (FOXP-1) gene. Children with FOXP-1 syndrome often experience intellectual disabilities, language difficulties, autism spectrum disorder, hypotonia and congenital anomalies. Most of these children also have walking difficulties. A clear description of these difficulties and gait pattern with treatment options, has not previously been reported.

Patients and Methods: In our case series report we describe the walking difficulties and gait abnormalities of 3 children, all boys, with FOXP-1 syndrome using gait analysis. Gait analysis provides a quantitative description of gait patterns by combining data of different sources such as kinematic data, kinetic data, video recording and electromyography.

Results: The most prominent abnormalities in the gait analysis of the three children with FOXP-1 syndrome were: ankle plantar flexion, and knee- and hip flexion in midstance. All three patient had reduced range of motion (ROM) of their gastrocnemius, two of their soleus as well. All patients were treated with serial casting in order to reduce toe walking and improve gastrocnemius ROM, preceded by botulinum toxin A injections of soleus and/or gastrocnemius in two patients. All patients had improvement of gait after the treatment. To preserve the ROM, rigid carbon fibre (ankle-) foot orthoses were applied.

Conclusion: Our case series show for the first time that children with FOXP-1 syndrome may have specific gait abnormalities. Gait analysis in these children can help to guide targeted treatment of walking problems.

Relevance for users and families:

This study shows the first Results of walking difficulties and gait abnormalities in children with FOXP-1 syndrome and these Results are very important for defining symptomatic treatment of these children.

Developing a National cerebral palsy (CP) register in Ireland – a feasibility study

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Introduction: Developments globally in the epidemiology of CP are largely driven by population registers. The reasons for the decline in the prevalence of CP in Europe and Australia between 1980 and 2003 are likely multiple and improving understanding of this is essential to managing risk. National registries are also critical to data collection in terms of selected interventions and outcomes. The overall aim of this feasibility study was to provide information and evidence for the establishment of an Irish National Cerebral Palsy (CP) Register.

Methods: A literature review and consultation with relevant stakeholders informed the options for an appropriate design for the register. Methods to achieve our objectives are based on those developed by the surveillance of CP in Europe (SCPE, 2000). A pilot test was carried out in a defined catchment area (composed of multiple disability agencies) to test the dataset and identify challenges with the notification, consent and ethical approval processes.

Results: Twelve children were notified to the pilot. Risk factors for CP were recorded. Acquiring ethical approval and negotiating data sharing agreements from multiple sites is a significant undertaking and needs to be considered and planned for the implementation of a national register.

Conclusion: This study confirms the utility of identifying children with CP using a defined dataset. Challenges for a national registry have been identified – namely that the small sample size does not allow accurate calculations for incidence and prevalence in the study population and the problem of gaining approval across multiple disability service providers.

Relevance for users and families:

Improving the health of people with physical and intellectual disability has become a worldwide priority, articulated by the United Nations (UN) Convention on the Rights of Persons with Disability (UN, 2007). We are confident the register will be part of this agenda by improving outcomes for Irish people with CP through the promotion of more equitable care benchmarked against international eligibility and entitlement scenarios, as well as changing attitudes/approaches to the management of CP.

Prevalence of Severe Neurological Impairment in Ireland – A Study of National In-Patient Point Prevalence Data

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Introduction: Children with Severe Neurological Impairment (SNI) are understood anecdotally to have frequent contacts with paediatric hospitals, and inpatient stays appear frequent and prolonged. The current number of children fulfilling the definition of SNI in Ireland is unknown. Extrapolation of international data on similar cohorts to the Irish population suggests there are up to 500 children with SNI out of the approximately 1 million children in Ireland. This study aims to examine in-patient point prevalence of SNI across paediatric units in Ireland.

Methods: An invitation to participate in national point prevalence data collection was distributed to each of the 20 paediatric centres. Data was collected on 2 days per month over 6 months with data collection points spread between Spring/Summer and Autumn/Winter 2022. In-patient numbers with SNI were collected along with numbers relating to the admitting discipline, scheduled vs unscheduled care and if the admission was likely to be prolonged (>5 days).

Results: Each of the 20 centres responded to the invitation to participate. Data from the 2 large tertiary centres showed consistent point prevalence rates from 8-14% and 15-28% while data from the smaller and regional centres had consistent figures from 2-7%, implying that the majority of inpatient care is provided in the larger tertiary units.

Conclusions: Despite comprising a very small percentage of the Irish paediatric population, children with SNI are disproportionately represented in acute paediatric beds, particularly in tertiary centres. Healthcare resources need to be directed at supporting care closer to home and supporting active discharge.

Relevance for users and families:

This research provides evidence on the extent of inpatient healthcare use for children with Severe Neurological Impairment by examining the numbers of inpatients in every paediatric ward on the same days over 6 months of the year. This information is extremely valuable in advocating for resources to improve care in the community and facilitate rapid access to appropriate care to enable children and families to spend as much time as possible in the home setting.

A new mindset for SMA Type I, accompanying them towards the future.

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Introduction: Classically, Spinal Muscular Atrophy (SMA) Type I presented extremely severe clinical features. They never achieve independent sitting and finally develop respiratory failure and die before 24 months old. New pharmacological treatments have lead us into a new phenotype surviving beyond two years and developing new motor and functional abilities. The aim of this study is to describe the health and function status of the new SMA Type I.

Patients and Methods: 50 genetically confirmed SMA1 subjects were included, approximately 83% of the patients of the Spanish SMA Patient-Reported Registry (60 on December 2021). A descriptive study was conducted through patient questionnaires and standardized tools administered in their natural environment (depending on their age and motor function).

Results: All children have received at least one pharmacological treatment. 56% have full oral feeding, 38% tube feeding and 6% combine both. 26% have tracheostomies, 44% of them need ventilatory support for the whole day. Regarding orthopedic status, 9% have suffered fractures, whilst 71% have scoliosis, 62% have hip subluxation or luxation and 30% have knee and/or hip contractures. On the other hand, 71% have and use a stander, and all have physiotherapy from 2 to 5 days per week. Around 20% are able to stand during at least 3 seconds and 44% use a walker.

Conclusions: SMA Type 1 is a different disease now, and we need to know new challenges in order to prevent alterations and enhance capacities.

Relevance for users and families:

Knowledge about the natural history of a disease is essential to clinical practice, for the accompaniment of the families and of course to minimise the impact of the disease enhancing motor performance and, consequently, participation.

International Delphi Study for the Development of a Common Dataset for Children with Severe Neurological Impairment

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Introduction: Children with Severe Neurological Impairment comprise a small but significant cohort of children who have rarely been studied together previously. Their diagnoses often exclude this group from other research. Key to advancing collaborative research on children with SNI is developing this common dataset for international collection of baseline and longitudinal data. This study aimed to use the initial dataset produced by scoping review in a Delphi process to achieve consensus on variables for a common dataset.

Methods: An international steering committee was formed, and the project was registered with the Core Outcome Measures for Effectiveness Trials COMET initiative (www.comet-initiative.org/ Studies/ Details/ 1976). The scoping review informed the initial variables. The initial draft dataset was fed back to the steering committee and the three-round Delphi study designed and consensus set in line with the Core Outcome Sets- Standards for Development and Reporting (COS- STAD/ STAR).

Results: 71 participants from 9 countries and 7 disciplines completed at least 1 round of the Delphi process. Participants rated the importance of the initial variables and suggested extra variables that they felt should be included. Following 3 rounds of Delphi surveys, 22 variables formed the core "minimum" dataset to be used in all datasets of children with SNI and 87 variables formed the secondary "additional" dataset.

Conclusions: This international common dataset will be central to future comparative and collaborative research. Ultimately, this will better inform expectant care and will support the development of evidence based clinical care pathways and guidelines.

Relevance for users and families:

This research produced two really important lists of data points to look at in all datasets and studies involving children with Severe Neurological Impairment, so that international centres can all collect them and together produce very helpful information for clinicians, researchers, policymakers and families.

The quality of life and stigma experienced by children with rare diseases and their families in Romania

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Introduction: There are over 900,000 children with rare diseases (CwRD) in Romania. With only a limited number of studies focused on this population, there is an urgent need to shed more light on the experiences of these children. This study aims to measure the parent/carer reported quality of life (QoL) of CwRD in Romania, and to establish the extent of stigma faced by parents or primary carers of CwRD.

Patients and Methods: A questionnaire consisting of demographic information, and 2 validated questionnaires - Paediatric Quality of Life (PedsQL) and adapted Parental Perception of Public Attitudes Scale (PPPAS) - were used. Participants (parents or primary caregivers of CwRD aged 2-16y/o) accessed the online survey in Romanian via the Qualtrics platform.

Results: Preliminary survey data collected between October-November 2022 comprising 53 participants has indicated that the average QoL on a scale of 0-100 is 42 demonstrating a critical need for intervention. Data suggested that 58.5% of children 'always' or 'often' experience difficulties with their school functioning and 49% of children 'always' or 'often' have problems with their social functioning. More than half of parents also indicated that they believe people talk poorly about them due to their child's condition. Data collection will continue until January 2023.

Conclusions: Data collection is ongoing, however CwRD in Romania experience barriers to participation, a decreased QoL, and moderate levels of stigma. As such, findings from this research suggest that there is a need for increased support and interventions aimed at CwRD and their families.

Relevance for users and families:

Only a limited amount of research on CwRD in Romania presently exists in the literature, with no previous studies describing the lived experience, quality of life, and experiences of stigma of CwRD and their families. As such, this study raises awareness and also hopes to inform interventions aimed at improving QoL and reducing experiences of stigma of CwRD and their families in Romania.

"We are thrown out of the nest"- Children with spina bifida transitioning into adult care.

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Introduction: Due to medical advances, an increasing number of adolescents with spina bifida are experiencing the transition to adult care. Consequently, more autonomy and reliability as well as specific knowledge about their disease are expected of them, as they gradually take over responsibility from their parents. These are a big steps for them and a challenging process that should be supported by specially tailored measures.

Methods: In a praxis development project an interprofessional working group developed recommendations for the transition process (TP). Additionally, a project group created, based on the "Ready-Steady-Go" programme developed at Southampton Children's Hospital, new questionnaires adapted to the Swiss healthcare system and translated those into easy language. After then, those questionnaires were implemented into praxis.

Results: Our first experiences with the new questionnaires and protocol based on the recommendations show that in collaboration with professionals the adolescents determined which everyday and medical topics from the questionnaires were relevant for their TP. Thus, the adolescents were cautiously attaining their greatest possible independence while parents were supported in handing over responsibility. Furthermore, support needs were identified and could be addressed timely.

Conclusion: Coordination and close supervision are crucial during the TP to integrate necessary measures into the new daily routine. Families need constant assistance from a care coordinator (CC) like an advance practice nurse (APN). Special attention needs to be paid to promoting self-care and to communication with professionals as well as to sensitive issues such as sexuality or mobbing.

Relevance for users and families:

The TP must be based on long-term considerations so that adolescents, parents and professionals have time to prepare for the transition to adult medicine and the upcoming changes. APN or CC are in an ideal position to coordinate and support the TP.

Understanding the use of digital technologies to provide disability services remotely during the COVID-19 pandemic; a multiple case study design.

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Introduction: People with disabilities often face barriers to accessing the services and supports they need to live healthy and independent lives. These barriers have been intensified by the Covid-19 pandemic. In an attempt to reduce the impact of the Covid-19 pandemic on the health of people with disabilities, many service providers in Ireland used digital technology to deliver services remotely.

Patients and Methods: A multiple case study design was used to explore the acceptability of using digital technology to provide services during the Covid-19 pandemic and identify barriers and facilitators to implementation. Semi-structured interviews were conducted with 40 people with disabilities, their parents and service providers from three cases. Data collection and analysis were informed by the Consolidated Framework for Implementation Research (CFIR).

Results: Based on CFIR constructs, notable facilitators included bottom-up and top-down development, positive perceptions of online services and perceived advantage over in-person delivery, compatibility of platforms with assistive technology, accessible knowledge and information, positive leadership engagement, availability of resources and increased self-efficacy of service users and providers. Barriers to implementation included the complexity of steps required to access online services, challenges with audio, video and feature quality, broadband, devices, and assistive technology costs, restrictive data protection regulation, incompatibility of online delivery with existing workflows, uncertain funding and deprioritisation of online services as circumstances changed during the Covid-19 pandemic.

Conclusion: The findings will support researchers and practitioners to develop or select strategies to address barriers that impede implementation and leverage facilitators to support the implementation of online services.

Relevance for users and families:

Digital technology has the potential to improve the accessibility, quality and equity of services for people with disabilities. This research highlights the benefits of using technology to access services remotely as well as the barriers and facilitators to using it. Findings will support organisations to overcome barriers that prevent people from using technology to access services, and therefore ensure the technology is optimally used to improve accessibility and equity of services for people with disabilities.

Universal data collections, including the ICF

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Introduction: UNICEF states that millions of children with disabilities around the globe continue to be left behind. Often, this neglect is the result of limited data. Over 70 percent of rare conditions have a genetic cause and manifest in childhood. One genetic defect usually causes a variety of disease manifestations, coded with the International Classification of Disease. We questioned adult persons with Shwachman Diamond Syndrome (SDS) using ICF terminology on activities and participation.

Patients and Methods: SDS is a rare ribosomopathy manifesting with pancreas insufficiency, metaphyseal dysplasia, developmental disability and neutropenia before age of 5 years. Children are hospitalized for bacterial infections, failure to thrive and skeletal dysplasia. We selected 12 ICF-d domains from the short autism core set affecting SDS. 5/10 adults with SDS responded to the adjusted SDS core set questionnaire.

Results:

Table number of responders with a score of .2 or more, with or without support.

ICF-d associated with SDS:

820 School education 5

210 Undertaking a single task 4

610 Acquisition of place to life 4

640 Doing house work 4

720 Complex interpersonal interactions 4

850 Remunerative employment 4

240 Handling stress and other psychologic demands 4

920 Recreation and leisure 3

Conclusion: Lack of appropriate school education has a major impact on adults with SDS. The developmental disorder, recurrent illness and hospitalisation may all have effected school education. Therefore we suggest the ICF to be associated with a rare disease coding capturing the ICD registrations. To ensure no one is left behind.

Relevance for users and families:

Using the ICF-d scores associated with a rare disease classification individuals with a rare condition can generate data in electronic health systems. Data on the effect of having a rare condition on well-being will become available. These data can be associated with clinical data such as the ICD.

Effectiveness of physical therapy for improving gait and participation in the community in children and adolescents with Cerebral Palsy: randomized clinical trial pilot study

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Cerebral Palsy is a non-progressive lesion of the Central Nervous System, with a wide spectrum of impairments at body structure and function, which has a great impact at activity and participation in the environment. Children and adolescents with Cerebral Palsy present limitations in gait function both at the level of body structure and activity and improving these aspects is one of the main therapeutic objectives in their treatment.

The aim of this clinical trial is to verify that a Physiotherapy intervention that combines face-to-face sessions with telecare in natural settings is effective in improving the functional activity of walking and participation in the environment of children and adolescents with Cerebral Palsy.

A randomized clinical trial pilot study was developed in 12 people aged 6 to 17 years old, diagnosed with Cerebral Palsy.

Intervention group (n=6) received 12 Physiotherapy sessions based on specific tasks directed to objectives; treadmill gait training; and 6 telehealth sessions of a therapeutic education program. Control group received the same telehealth Therapeutic Education program.

The variables, participation (CAPE), gait speed (10MWT), gait endurance (6 MWT), gross motor function (GMFM-SP) and balance (PBS), were collected at baseline (V0); after groups intervention (V1); and (V2) 3 months after baseline (V2).

There was an improvement in gait and balance in favor of the intervention group ($p<0.05$). There was not a statistically significant difference in participation between groups.

Therefore the proposed Physiotherapy program is effective on the gait and balance improvement in children and adolescents with Cerebral Palsy.

Relevance for users and families:

The intensity of participation is influenced by multiple factors, among which independent mobility stands out, through the functional activity of walking. Children and adolescents with Cerebral Palsy present limitations in gait function both at the level of body structure and activity and improving these aspects is one of the main therapeutic objectives in their treatment.

Art therapy in child (re)habilitation

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Introduction: The application of art therapy in the multidisciplinary process of (re)habilitation has proven to be successful in patients with diseases of the central and peripheral nervous system, but it is still insufficiently used in daily clinical work. The aim of the work was to show the application of art therapy in the (re)habilitation of children and youth.

Patients and Methods: The research was conducted at the Children's Habilitation and Rehabilitation Clinic of the Institute for Health Care of Children and Youth of Vojvodina Novi Sad, Republic of Serbia, during the period of the current covid-19 pandemic, March-September 2020. The respondents independently chose the drawing technique, the number of drawings, as well as the topic.

Results: 33 respondents participated in the research: 27 children (14 boys and 13 girls) and 6 caregivers. Of these, 14 children (51.85%) were treated in outpatient settings, and 13 (48.15%) in inpatient settings. In the total sample, 8 respondents (24.24%) were aged 3-6 years, 8 (24.24%) aged 7-10 years, 6 (18.18%) aged 11-14 years, and 11 (33.34%) older than 15 years. A total of 45 drawings were obtained during the (re)habilitation process. The most common was drawing with wooden crayons, 18 drawings (40%) and ballpoint pen, 10 drawings (22.22%).

Conclusion: Involving hands in bimanual drawing activities, improving attention and motivation when working in a small group can be an additional tool in the treatment and (re)habilitation process.

Relevance for users and families:

Involving hands in bimanual drawing activities, improving attention and motivation when working in a small group can be an additional tool in the treatment and (re)habilitation process.

Implementation of the ICF approach to target participation in a child with Cockayne syndrome: a case report

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Introduction: The patient's perspective is vital to physiotherapy programming, particularly with respect to participation. This case report of a child with Cockayne syndrome (prevalence 1/500,000 births) used an ICF approach.

Patients and Methods: A 30-month-old child presented with severe postural control deficits including head instability. His limited range of shoulder motion affected upper limb function. These body function and structure issues impacted his Activities of Daily Living, (inability to take off his shirt or throw a ball). The family's SMART goal was for their son to participate in games and everyday family routines with his brothers. Trunk control was assessed (SATCo), together with functional independence (PEDI) and participation (YC-PEM). Physiotherapy intervention comprised head/trunk control training, a standing programme, and postural aids, with simplified games to play with his brothers.

Results: After seven months, trunk control improved from having no head control to demonstrating static and active control at the Mid Thoracic segment. The PEDI (Functional Abilities´s domains) score increased by 36 points while the YC-PEM revealed greater involvement in both school and home environments. An increase in active shoulder mobility, together with improved trunk control, meant that the child was able to play ball with his brothers. His motivation had also increased, enabling new activities such as undressing himself to join bath-time with his brothers and participating in family fun time.

Conclusion: Programme planning was facilitated by using the IFC approach with a focus on participation, achieving the goal of interactive ball games and greater functional independence.

Relevance for users and families:

Limited life expectancy makes goal setting a greater challenge for children with severe disability but close involvement of the family and use of the ICF approach can empower the child in his environment.

The quality of life and stigma experienced by children with rare diseases and their families in Romania

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Introduction: There are over 900,000 children with rare diseases (CwRD) in Romania. With only a limited number of studies focused on this population, there is an urgent need to shed more light on the experiences of these children. This study aims to measure the parent/carer reported quality of life (QoL) of CwRD in Romania, and to establish the extent of stigma faced by parents or primary carers of CwRD.

Patients and Methods: A questionnaire consisting of demographic information, and 2 validated questionnaires - Paediatric Quality of Life (PedsQL) and adapted Parental Perception of Public Attitudes Scale (PPPAS) - were used. Participants (parents or primary caregivers of CwRD aged 2-16y/o) accessed the online survey in Romanian via the Qualtrics platform.

Results: Preliminary survey data collected between October-November 2022 comprising 53 participants has indicated that the average QoL on a scale of 0-100 is 42 demonstrating a critical need for intervention. Data suggested that 58.5% of children 'always' or 'often' experience difficulties with their school functioning and 49% of children 'always' or 'often' have problems with their social functioning. More than half of parents also indicated that they believe people talk poorly about them due to their child's condition. Data collection will continue until January 2023.

Conclusions: Data collection is ongoing, however CwRD in Romania experience barriers to participation, a decreased QoL, and moderate levels of stigma. As such, findings from this research suggest that there is a need for increased support and interventions aimed at CwRD and their families.

Relevance for users and families:

Only a limited amount of research on CwRD in Romania presently exists in the literature, with no previous studies describing the lived experience, quality of life, and experiences of stigma of CwRD and their families. As such, this study raises awareness and also hopes to inform interventions aimed at improving QoL and reducing experiences of stigma of CwRD and their families in Romania.

Music Assisted Therapy - A pilot study in children with neurodevelopmental disorders

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Introduction: Music is used as complementary therapeutic resource it is a fundamental pillar in intervention groups of children with neurodevelopmental diseases. In this line of thought, the idea arose to implement a project in team work with professionals from different specialities with training in the music area.

Patients and Methods: The target audience includes children with different levels of neurodevelopmental diseases, from a Rehabilitation Center, with a range 3 to 7 years old age. The children will be randomly assigned to 2 groups: a rehabilitation group (RG) and a control group (CG). The both groups will be evaluated at the beginning of the intervention and after 6 months. Will be used in the two assessments moments: the Moatt's Test - hearing screening instrument, the Hearing and Language subscale of the Griffiths Mental Development Evaluation Scale and the Pre-verbal Communication Scale. The intervention activities with the RG will last 30 minutes and will be held once a week in a therapeutic environment, to provide a comfortable, safe and self-regulation behaviour.

Results: According to the Results of initial evaluations carried out, we have a relatively homogeneous group, with an age of mental development under 1 year at the hearing and language subscales. Each element has its specific needs and a different learning process, but through observation.

Conlcusions: we found that music is their common point and that it facilitated the process of interaction and acquisition of learning.

Relevance for users and families:

Several studies highlight music as a pillar of great importance for the development of verbal and non-verbal communication skills, social skills, sensory skills, motor skills , cognitive skills and emotional skills. We hope that this group of children could have in the future a better modelation of their behaviour and an improvement in oral communication. Therefore we will have good Results in social adaptation and inclusion.

Development of the impaired hand during the first 15 months of life in infants with unilateral cerebral palsy (UCP)

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Introduction: We use data from the REACH RCT to identify different trajectories of development of impaired hand function for infants with UCP aged 3-15mths corrected age (c.a.) and describe characteristics of each trajectory group.

Study participants and setting: 63 infants (58% male) with UCP between 3-9mths c.a. were randomized to receive modified constraint-induced movement therapy or bimanual therapy.

Materials/Methods: Infants were assessed at baseline, 6mths later, then post intervention at 12-15mths c.a. using the Hand Assessment of Infants. Group-based trajectory modelling identified subgroups of infants with similar trajectories. Associations between demographic variables and trajectory group membership was investigated using multinomial logistic regression.

Results: There were 157 infant assessments. Three groups of children were identified based on developmental trajectories of impaired hand function: “Low” 29%, Moderate” 35%, and “High” 36%. The relative risk ratio of being in the low or moderate group relative to high group increased by 16% (95%CI 1.02-1.32, p=0.03) and 14% (95%CI 1.01-1.29; p=0.03) respectively for each one week increase in gestational age. Boys were more likely to be in the low relative to high group (RRR=7.22; 95%CI 1.6-32.5; p=0.01). At 12-15mths c.a., infants in the low compared to high group had significantly poorer cognition measured on the Bayley’s (MD 13.1, 95%CI 3.5-22.6; p=0.008), and hand function on the MiniAHA (MD 49.7, 95%CI 43.0-56.3; p<0.001).

Conclusion/significance: Three distinct trajectories of impaired hand function were identified for infants with UCP. Boys born closer to term were at an increased risk of being in the low relative to high group.

Relevance for users and families:

We showed three distinct trajectories of development of impaired hand function for babies with unilateral cerebral palsy and the importance of gestational age at birth and sex on the risk of having a poorer trajectory of development of hand function.

Construct validity of the both hands assessment using wrist-worn accelerometers

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Introduction: The Both Hands Assessment (BoHA) measures upper-limb bimanual performance for children with bilateral cerebral palsy (CP). Further psychometric studies to confirm its validity have been recommended. Accelerometers objectively quantify upper limb activity performance. The aim was to evaluate the construct validity of the BoHA using activity of the upper limbs detected by accelerometry.

Patients and Methods: Children with bilateral CP (n=44, 27 boys, aged 9.1±1.6 years; Manual Ability Classification Scale I=15, II=22, III=7) completed a BoHA while wearing a triaxial accelerometer on each wrist. BoHA measures (each-Hand sub-scores, percentage difference between hands, units) accelerometry measures (mean activity for each hand, mean activity asymmetry index and total mean activity) were calculated. Associations between measures was determined using linear regressions.

Results: There were significant, positive associations between BoHA Units and total mean activity (B=0.86, 95%CI:0.32,1.40), BoHA percentage difference between hands and mean activity asymmetry index (B=0.95, 95%CI:0.75,1.15), and BoHA each-hand sub-score and mean activity for the non-dominant hand (B=1.71, 95%CI:1.16,2.28), but not for the dominant hand.

Conclusion: This study provides further evidence for the construct validity of the BoHA as a measure of upper limb activity performance. Wearable wrist sensors such as accelerometers capture and quantify gross upper limb movement in children with CP but cannot measure fine finger movements captured by the BoHA.

Relevance for users and families:

Relevance for users and families: The Both Hands Assessment (BoHA) claims to measure how children with bilateral CP complete tasks with both hands during everyday tasks. We used wrist-worn activity monitors to measure how much children used their arms during the BoHA assessment and found good correlation between measurements from the activity monitor and BoHA, which means we have more evidence to support the use of the BoHA to assess upper limb activity.

Effectiveness of treatment with nusinersen in our pediatric patients with spinal muscular atrophy (SMA)

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Introduction: Spinal muscular atrophy is an autosomal-recessive disorder characterized by degeneration of motor neurons in the spinal cord, caused by mutations in the survival motor neuron 1 gene, SMN1. In recent years, some drugs have appeared to improve the natural evolution.

We carried out a study to observe the effectiveness of nusinersen (Spinraza ®) in our patients.

Patients and methods: Prospective cohort study with six pediatric patients, all of them SMA type 2 treated with nusinersen. We evaluated the effectiveness according to three validated scales: CHOP-INTEND; Expanded Hammersmith Functional Motor Scale (HFMSE); RULM. The evaluation process was adapted according to the motor milestones reached by the patient.

The follow-up period was 52 months.

Results: We have six pediatric patients.

Four of them increased puntuation from baseline in the HFMSE, one of them stayed and one got worse (Total percentage increase 14%). Two patients increased the CHOP puntuation, three decreased and one had no variation (Total percentage decrease 1%). According to RULM scale, two increased the puntuation, two stayed and two got worse (Total percentage increase 24%)

The walking patient improved her six-minute walk test in 160 metres, 66% in percentage terms.

Quality of life was also assessed.

Conclusions: Among pediatric patients with SMA, those who received nusinersen were more likely to have improvements in motor function. Early treatment may be necessary to maximize the benefit of the drug. Children and families observe improvement in their everydaylife and quality of life, in addition to the benefits observed in the rating scales.

Relevance for users and families:

RELEVANCE FOR USERS AND FAMILIES

The emergence of new drugs on the SMA horizon allows us to improve patient survival and quality of life, without forgetting that we must quantify the developments in order to set our sights on the new challenges that arise, especially in the youngest children.

Self-care capabilities and hand function among preschool children with unilateral or bilateral cerebral palsy – a registry based study.

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Introduction: The role of hand function in everyday tasks is well established, yet the association between self-care capability (PEDI) and hand function for young children with cerebral palsy is unclear. The aim of this study was to compare self-care capabilities between children with unilateral (UCP) or bilateral cerebral palsy (BCP), and explore associations between self-care and hand-function.

Patients and Methods: Totally 87 children classified at Manual Ability Classification System (MACS) I-III (UCP n=61, BCP n=26, males n=51, mean age 49 months) and assessed with the PEDI functional skills scale for self-care and Assisting Hand Assessment (AHA) or Both Hands Assessment (BoHA). Cross-section study with data from the Norwegian Quality and Surveillance Registry for Cerebral Palsy (NorCP).

Results: No significant differences in self-care capabilities between children with UCP or BCP. Significant differences in PEDI scores were seen between MACS levels I-II and I-III for children with BCP, yet not for children with UCP. A small correlation (r=0.3) between PEDI and AHA was found for children with UCP, a large correlation (r=0.6) was found for BCP. Children with BCP classifies with symmetric hand use (BoHA) demonstrated higher PEDI scores.

Conclusion: Children with UCP and BCP demonstrated similar self-care capabilities. There were significant differences in PEDI between MACS levels only for children with BCP. The different correlation Results between bimanual hand-use (AHA or BoHA) and PEDI may illustrate that different aspects of hand-use are measured in the two tests and that patterns of hand-use in self-care tasks are different between the two groups.

Relevance for users and families:

The different Results between UCP and BCP may highlight some major differences in how children with UCP and BCP use their hands during self-care tasks. The findings point towards the importance of a holistic approach to the assessment of children with CP, and the importance of using different interventions for different groups. Furthermore, when seeking information about the complex concept of children's self-care capabilities, assessing manual abilities or bimanual hand function may not be sufficient.

Usability of task-based and process-based assessments in early powered mobility intervention

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Introduction: Clinicians and educators use assessments to identify an individual's abilities and goals to tailor a powered mobility intervention session. There are two approaches to what performance characteristics or qualities to evaluate. Task-based approaches evaluate an individual's performance of specific, standardized tasks. Process-based approaches observe performance indicators to evaluate where an individual falls along the continuum of the tool-use learning process.

Materials and Methods: Characteristics of task-based and process-based assessment instruments developed for powered mobility were compared and analysed for usability with individuals in different powered mobility learner groups (exploratory, operational, or functional).

Results: Process-based approaches help evaluate an individual's tool-use understanding through observation of a tool-use situation and are independent of age, diagnosis, and performance of specific skills. Process-based assessments are especially useful for tyro learners who are either beginners in learning and/or have cognitive limitations. Task-based approaches help evaluate an individual's skilled performance of the described tasks necessary for safe and secure use of a powered mobility device. Task-based assessments are useful for older infants and children who are emerging into the functional powered mobility learner group and are ready to integrate powered mobility use into their everyday lives.

Conclusion: Understanding what distinguishes task- and process-based approaches may assist clinicians/educators in choosing the assessment that best meets a specific individual's needs, abilities, and level of tool-use understanding. A combination of task-and process-based assessments can be useful for functional learners who are integrating powered mobility-use into other activities and who are candidates for an individually prescribed powered wheelchair.

Relevance for users and families:

Understanding the characteristics and differences of the two assessment approaches is important especially for users and families of infants and children in exploratory or operational powered mobility learner groups. Knowing what indicates success in the early phases of the learning process is valuable and may help users and their families to be actively involved in, and stay engaged in, powered mobility intervention sessions.

Implementation of evidence-based practice in a rare chromosomal disorder: a child with duplication 15q syndrome [invdup(15)]

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Introduction: Physiotherapy is patient-tailored but generally based on a standardised model. Such models are not available for patients with rare conditions. This case study used a 'best evidence review approach to manage hypotonia in a child with Invdup (15) (prevalence 1/30,000 births).

Patients and Methods: A 7-month-old boy presented with hypotonia with no head control or voluntary antigravity movement and lack of personal interaction with his parents. A literature review identified best available evidence and addressed hypotonia with a programme aimed at independent sitting consisting of i) specific graded trunk control exercises to enable maintenance of the neutral vertical posture ii) use of a custom-made plaster seat at home/nursery and iii) home activity programme using play. This was guided by the parents´ SMART goal of "To be able to play with our son on the swings in our city park".

Results: After two months intervention, the child could orient his head (maintaining horizontal gaze) and maintain a stable sitting posture while using his arms for play and not for support. He achieved development milestones including rolling, coming to all fours (hand and knees) and standing with support. This increased his ability to participate in an unadapted environment, evidenced by achieving the parents' goal of using a regular swing in the park.

Conclusion: A physiotherapy programme based on best available evidence intervened at the body structure and function level with resulting enhancement of both activity and participation.

Relevance for users and families:

This evidence-sourcing approach is especially pertinent for families of children with rare conditions.

The effect of bimanual intensive functional training on sensory hand function in children with unilateral spastic cerebral palsy

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Introduction: Motor impairments are the hallmark of children with unilateral spastic cerebral palsy (USCP). Yet they also often experience sensory impairments. Intensive bimanual training is well known for its improvement of motor abilities, though its effect on somatosensory impairments is less known.

Objective: To investigate whether bimanual intensive functional therapy without using enriched sensory materials improves somatosensory hand function.

Patients and Methods: Twenty-four participants with CP (12 – 17 years) received 80-90 hours intensive functional training aimed at improving bimanual treatment goals. Somatosensory hand function was measured prior to training, directly after training and at 6 months follow-up. Outcome measures were: proprioception measured by thumb and wrist position task and thumb localisation task; vibration sensation; tactile perception; and stereognosis.

Results: While improving on their individual treatment goals, participants also showed significant improvements in one out of two tests for proprioception, vibration sensation, tactile perception and stereognosis of the more affected hand after training. Improvements were retained at six months follow-up. Perception measured by the thumb localisation task showed no improvement after training.

Conclusion: Somatosensory function including tactile perception, vibration sense, stereognosis and proprioception of the more affected hand in children with USCP improved after intensive functional bimanual training without environmental tactile enrichment.

Relevance for users and families:

Intervention to improve somatosensory function in children with USCP is understudied and of importance, while somatosensory function influences motor function and activities of daily living.

Efficacy of radial extracorporeal shock wave therapy in the local treatment of muscle hypertonia in patients with cerebral palsy

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Hypertonia is the most common motor disorder in Cerebral Palsy (CP). The approach is complex and presents a challenge for the rehabilitation team. Radial extracorporeal shock wave therapy (rESWT), has been established in recent years as an effective, non-invasive alternative without significant side effects for the management of hypertonia in patients with CP

Quasi-experimental pre-post study of repeated measures without a control group where the response to the intervention with rESTW was evaluated before the treatment, immediately, 3, and 6 months after treatment. Inclusion criteria were CP diagnosis, age over 6 years, and GMFCS (Gross Motor Function Classification System)I, II, and III. The main variable was the functional motor response to treatment through the timed Up and Go test and the 10-meter walk test.

28 of the 79 patients (37.3%) were under 18 years old., 89% (25) present spastic CP, 3.6% (1) dystonic, and 7.1% (2) mixed CP;

The soleus and gastrocnemius were 39.3% (11) of the muscles treated, hamstrings 10.7% (3); and adductors 3.6% (1).

Statistical analysis used was a mixed linear model of repeated measures. Up and Go test find from baseline (9.06 seconds) significantly reduces in visit 1 (7.19 seconds) and it lasts over time. The 10m Walking test, increasing from baseline (1.65m/seg) to Visit 1 (1.92m/seg) with a tendency to maintain. In both tests, we confirm the functional effect after the use of rESWT with p-value < 0.001

We found a functional improvement in patients treated with rESTW and without significant side effects

Relevance for users and families:

The Results can suggest a functional improvement with the treatment in patients with spasticity, with an accessible tool and non-invansive, with minimium of risk for the patients and propabaly in our cohort without side effects, and a sufficiently good experience for them and their families. There are no sufficient support data published actually to use as a complement to the other treatments that we have on our hands

Delivering intrathecal Nusinersen using interventional radiology for children with spinal muscular atrophy

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Introduction: Spinal muscular atrophy (SMA) is a rare genetic disease that Results in the loss of motor neurons and progressive muscle wasting. In June 2019, Nursinersen was made commercially available for all patients with SMA under the age of 18 in Ireland. The drug can slow the progression of the disease and improve muscle function.

Scoliosis is a complication associated with SMA, with most patients requiring orthopaedic surgery to place spinal rods. There were some concerns in relation to the ability to administer this drug for patients with scoliosis, and the potential requirement for general anaesthesia and PICU beds. Repeated GA was not an option for these patients due to associated respiratory compromise. Therefore, interventional radiology (IR) is essential to successfully treat these patients.

Patients and Methods: There are currently 11 patients being treated with intrathecal Nusinersen under IR in Children's Health Ireland at Tallaght. Nine of whom use nitrous oxide analgesia. The procedure is done as a day case and takes approximately 30 minutes. Time from admission to discharge is less than five hours.

Results: 100% of the patients remain on treatment with no significant complications to date. Patients receive a safe and efficient service without the need for repeated GA, PICU or hospital admissions.

Conclusions: IR and nitrous oxide analgesia have been hugely successful in the delivery of intrathecal Nusinersen for children with SMA and complex spines. Without the involvement and clinical expertise of the consultant interventional radiologist, it would not have been possible to treat these patients.

Relevance for users and families:

Relevance to users and families: Anecdotally, patients and families describe their satisfaction with the procedure, associated clinical outcomes and patient and family experience. The team has recently circulated a patient and family satisfaction questionnaire. Results are pending.

Attitudes of students with regular development towards students with developmental difficulties

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Inclusive education is one of the most significant challenges and initiatives in education faced by educational communities around the world (Sharma, Forlin and Loreman, 2008, according to Martan, 2018, according to Juraić, 2020). The education system of the Republic of Croatia has the same problems.

In this research it is important to explain what attitude is. Attitude is an acquired tendency to react either positively or negatively towards persons, objects, or situations outside of us, or towards our own characteristics, ideas, or actions (Zvonarević, 1985). Students with disabilities are not always well accepted by their peers (Igrić et al., 2015), which can result in rejection, and isolation.

The aim of this work is to examine the attitude of 36 5th grade students towards students with disabilities, as well as their willingness to act towards them who are educated in special classes at the Eugen Kumičić Elementary School, Slatina. It was created anonymous questionnaire with 13 questions and the students' task is to express opinion with the answers YES or NO. The Results show the positive attitudes of students towards students with disabilities: 92% of respondents think they could be friends with a student with disabilities, and 94% of the sample can imagine playing with them. The answers show that 100% of the respondents would protect students from a special department and think that they can be successful in certain activities. According to this, we can say that positive attitudes are the main prerequisites for successful inclusion.

Relevance for users and families:

The proposed paper shows how students with regular development who study in a regular school with special departments think, and what significance this has for today's inclusive society.

Medial gastrocnemius morphology after orthopedic surgery in a child with spastic cerebral palsy

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Introduction: To improve gait in children with spastic cerebral palsy (CP), the calf muscle can be surgically elongated, for instance with an incision at the muscle-tendon junction. We investigated the effects of this surgery on medial gastrocnemius (MG) morphology in a child with CP, and compared the Results with those of typically developing (TD) children.

Patients and Methods: Muscle-tendon unit (MTU), muscle-belly, tendon, and fascicle length, and muscle volume were determined with 3D ultrasound for a boy with spastic CP (13 years, GMFCS I) one week before and 21 weeks after surgery (including a period of intensive physiotherapy), and compared to reference data of 20 TD children (10±3 years). Lengths were normalized to tibia length and volume to body weight. One-sample t-tests were conducted to compare the CP case with TD reference data.

Results: Before surgery MTU, muscle-belly length, and muscle volume were significantly lower and tendon length longer in CP compared to TD. Fascicle length was similar to TD. After surgery MTU, muscle-belly and tendon length respectively increased with 11%, 1% and 18%. Fascicle length decreased 16% and muscle volume increased 8%. After surgery, only MTU length was similar in CP compared to TD while muscle-belly, tendon and fascicle length and muscle volume significantly differed from TD.

Conclusion: In this case, the MTU lengthening following MG surgery was mainly explained by tendon elongation. The simultaneous increase in muscle volume and reduced fascicle length could be explained by the combined effect of fascicle hypertrophy and increase in pennation angle.

Relevance for users and families:

Quantifying surgical effects on muscle-tendon morphology helps to monitor whether treatment aims were met. In this case, MTU lengthening was achieved mainly by tendon elongation. However, the increase in MTU length may have improved the child's function during daily life and physiotherapy, explaining the increase in muscle volume.

Merosin-negative dystrophy as a cause of floppy infant syndrome - case series and literature review.

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Introduction: Merosine-negative muscular dystrophy (MDC1A) is a rare genetic disease, but it is the most common form of congenital muscular dystrophies causing clinical symptoms of floppy infant syndrome.

Patients and Methods: We present the literature review and the cases of two patients with the classic form of merosin-negative dystrophy. A 10-year-old girl and a 10-year-old boy, non-ambulatory, moving in a wheelchair, with a large scoliotic deformity of the spine and dislocation of the hip joints.

Result: Symptoms that can be observed in the neonatal period include weak crying, respiratory problems, and hypotonia and generalized joint laxity. Muscle weakness and hypotonia consequently lead to progressive, life-threatening respiratory failure, contractures in the upper and lower limbs, and spinal deformities. As a consequence, most children do not develop the ability to crawl, get up and walk and need the constant help of a caregiver in activities of daily living. Improving respiratory efficiency, controlling balance in the sitting position and maintaining an appropriate body weight are the basic goals of conservative therapy. The main indications for the correction of deformities of the spine, hips, knees and feet are contractures that make sitting or standing difficult. The goals of surgery are to prevent functional deterioration, improve function, facilitate sitting or standing, and adjust orthoses.

Conclusion: The most important risk factor affecting survival time in patients with MDC1A is lung function, which is associated with spinal deformity. Limb deformities often require surgical treatment, however, the patient's general condition and prognosis should be taken into account

Relevance for users and families:

Expanding knowledge and better understanding of the natural course of the disease and treatment perspectives by patients and their family members

Effectiveness of virtual reality to improve balance in children with cerebral palsy: a systematic review and meta-analysis with meta-regression

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Introduction: Cerebral palsy (CP) is a non-progressive neurological disorder and the main cause of physical disability in childhood. Children with CP suffer from difficulties with balance which result in limitations in everyday life. Virtual Reality (VR) has been proposed as a new treatment method to improve balance whilst increasing participants' motivation and engagement. The aim of this review was to systematically synthesise relevant literature to appraise current knowledge on the effectiveness of VR-based balance training in children with CP compared to physiotherapy without VR.

Patients and Methods: We conducted a systematic review with meta-analysis following the Cochrane Handbook. We searched in PubMed, CINAHL, Embase and PEDro for eligible studies until February 2022. A random effects meta-analysis was conducted in R to investigate static and dynamic balance. We assessed the quality of the evidence using the GRADE approach.

Results: We identified 143 randomized controlled trials and finally included 12 randomized controlled trials. Heterogeneity was large among the studies. Our Results show that VR training is more effective than standard physiotherapy for improving static as well as dynamic balance in children with CP, with little benefits to those with GMFCS-levels III-V. A meta-regression revealed that too much therapy per week seems to reduce the positive Results of a VR intervention.

Conclusion: VR is effective to improve static and dynamic balance in children CP with GMFCS-levels I-II, with little benefit in children with increased motor damage. The optimal dosage should be explored in view of how to integrate it with other training approaches.

Relevance for users and families:

Our study shows a great effect of balance training with virtual reality on the balance of children with cerebral palsy (SMD: 0.8). Therefore, it may be worthwhile to conduct regular balance training with virtual reality at home or in supervised physiotherapy. Children are motivated and can train in a playful way.

According to our research, the price for the purchase can vary depending on the device, but can basically be bought from 40 $.

Test retest reliability of technology based bimanual and unimanual task-specific strength in children with Cerebral Palsy, using the ADL-TTD, a newly developed test and training device.

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Introduction: Performing daily tasks is complex for children with Cerebral Palsy (CP). Lack of upper limb muscle strength and difficulties in coordinating their motor performance, affect their abilities to perform these tasks.

In clinical practice it's difficult to measure and train both components when performing a daily task. Therefore, we developed the ADL-TTD, an innovative device for testing and training task-specific strength and coordination with daily objects. We examined the test-retest reliability of the peak-force measurements during lifting tasks with the ADL-TTD in children with CP.

Patients and Methods: We included 47 children with unilateral spastic CP (8 till 18 years of age). The peak-force was measured during lifting a crate (bimanual) and during lifting a cup with non-affected (NAH) and affected hand (AH). Time between test-retest was 45 minutes to a maximum of 1 day.

Intraclass Correlation Coefficient (ICC) and measurement error (SEM) were calculated.

Results: CC values with confidence-intervals for all tasks were very high: Crate 0.97 (0.94-0.98), cup with NAH 0.95 (0.91-0.97) and cup with AH 0.99 (0.96-0.99).

The SEM (expressed in kilograms) was large for every task: Crate 6.0 kg, cup with NAH 2.99 kg and cup with AH 1.95kg.

Conclusion: Based on the high ICC value, it can be concluded that the ADL-TTD can discriminate well and thus can be used for diagnostic purposes. The evaluative use of the ADL-TTD is not yet recommended, given the large measurement error. Further research is needed in the direction of using the mean lifted weight instead of peak-force.

Relevance for users and families:

The ADL-TTD can be used to establish a reliable baseline for the start of a period of task specific strength training. Videogames are developed in the ADL-TTD to train task specific strength and sensors in the ADL-TTD provide targeted feedback of the coordination during lifting the objects. Training through video games fits well with children's interests and enables the motivation to train.

Current measurement practices and use of technology among Flemish pediatric physiotherapists

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Introduction: Evidence-based practice requires systematic use of standardised outcome measures to assess motor performance and evaluate treatment progress. It has also been suggested that technology-based assessments offer more objective and reliable outcome measures that could increase physiotherapy treatment efficacy. However, frequent implementation of outcome measures, let alone technology, seems limited in physiotherapy practices. The aim of this study was to determine the attitudes and adoption rate of assessment Methods and technology by Flemish pediatric physiotherapists.

Methods: An online questionnaire, evaluating the general demographics and attitudes towards technology and standardised measurement practices, was distributed among physiotherapists in Flanders, Belgium. Recruitment was performed through physiotherapy organisations, targeted mailing and social media.

Results: Of 310 completed questionnaires, 126 were completed by pediatric physiotherapists. The majority (75%) of this subgroup reported frequent use of outcome measures compared to 29% among non-pediatric physiotherapists ($p<0.001$). Lack of time, financial means and relevance were main barriers to implement standardised measurements. While 78% of pediatric physiotherapists reported to be interested in rehabilitation technology, only 15% agreed to be knowledgeable about current technologies in clinical practice and 38% reported to use no technology. The main barriers for technological integration were a lack of financial means, digital skills and time.

Conclusion: Frequent use of standardised outcome measures was reported to be high among Flemish pediatric physiotherapists. However, the use of technology in daily practice is more limited. Improved knowledge transfer and financial incentives may increase the implementation of both technology and standardised outcome measures among pediatric physiotherapists in Flanders.

Relevance for users and families:

The systematic use of motor assessment instruments enables therapists to evaluate the progress of their patients efficiently and objectively, enabling individualised and qualitative therapy. Technological tools may offer clinicians even more means to improve their interventions. With this study, we highlight the barriers therapists experience in the use of both types of tools. That way, both policy makers and researchers can aim to tackle these difficulties and allow physiotherapist to provide better aid to patients.

The development and validation of a cost of care questionnaire for children with Arthrogryposis Multiplex Congenita: A caregiver perspective

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Rare musculoskeletal (MSK) conditions (e.g., Arthrogryposis Multiplex Congenita (AMC)), are associated with enormous health impacts, affecting patients' health, and causing direct and indirect costs for their families/caregivers. Families have reported that MSK conditions result in significant economic impact, but the exact cost is unknown despite it being an emerging area of study. A recent literature review on cost studies in childhood disability, reports that researchers fail to mention or provide the questionnaire used, and the validation process of these questionnaires. Hence, this study's aim was to create (identify, develop, and access the feasibility of the measure while contributing evidence) a tool to measure the cost of caring for children with AMC from the caregivers' perspectives. This questionnaire was developed using an iterative design process that included a literature review, a review of existing measures, pilot testing, validation, and translation. 5 Caregiver representatives and 10 healthcare & other professionals were involved in developing, piloting, and validating this tool. The questionnaire was created in English and translated into French and Spanish. The questionnaire covers the following domain: Child and caregiver's demographics, Caregiver's sociodemographics, and Cost information (direct, indirect cost, and psychosocial costs). This tool was determined to be completed within 45mins of administration and is hosted on Qualtrics for electronic administration. The development and validation process of this tool will help other researchers to adapt this questionnaire for other studies, and develop similar questionnaires. Therefore, it supports economic evaluations of the impact of care on caregivers of children with disabilities.

Relevance for users and families:

The estimation of the cost of caring for a child with AMC aids both researchers and policymakers to make informed decisions on its impact on the healthcare system and motivates change in access to care. Therefore, by measuring and comparing the cost of care, healthcare decision-makers can benefit in setting up and prioritizing healthcare policies and interventions that are supposed to be implemented which in turn would benefit children with AMC and their families.

Families' perceptions and feelings during the diagnosis of hypotonia in children. Qualitative study.

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Introduction: Hypotonia is a feature of several pediatric conditions and determining its etiology is a challenging task. Families go through a long process until they find a diagnosis, or maintain the exclusion diagnosis of benign hypotonia. The objective of this study is to understand the difficulties and feelings of the families of children diagnosed with benign hypotonia during the diagnostic process.

Patients and Methods: A qualitative study through semi-structured individual interviews was performed. Ten caregivers of children with benign hypotonia between two and four years old participated. Interviews were recorded, transcribed verbatim, coded, and analysed thematically using MAXQDA.

Results: Caregivers generally found it difficult to get support from the pediatrician when they suspected that the child had a problem, often getting responses that everything was fine, and having to look for services themselves. They also experienced delays when carrying out tests and/or the lack of conclusive diagnostic tests, the lack of information, guidance, and professional support. Among their feelings during this phase, they expressed concern, misunderstanding, loneliness, fear, uncertainty, anger, frustration, and a feeling of being lost, wasting time, or being "on a roller coaster of emotions". When they started treatment and saw the child improve, they generally felt calm.

Conclusions: The findings of this study highlight the importance of the parent-professional relationship in the screening process and have important practical implications for health administrations to improve that process.

Relevance for users and families:

Increasing professionals' awareness concerning difficulties and feelings experienced by families during the diagnosis process of paediatric conditions with hypotonia, could improve care processes.

The psycho-social impact of having a child with severe neurological impairment in the family: A systematic review

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Introduction: Children with severe neurological impairment (SNI) have CNS disorders with impairments in motor and cognitive functioning, and medical complexity. In the context of providing holistic support to families with children with SNI there is a need to understand what the impact is on families of having a child with SNI. As children with SNI have a range of diagnoses a literature review is suitable for exploring commonalities and differences in parental experience across different diagnoses but similar impairments.

Patients and Methods: This study synthesised the existing literature on this topic. Searches were performed on PubMed, PsychInfo, and Cinahl. Inclusion criteria included primary research studies of children (under 18 years) with SNI that measured some aspect of psycho-social outcomes for family members. Papers are being reviewed for inclusion by two independent raters, and thematic synthesis will be performed on the Results from included papers.

Results: After removal of duplicates 797 papers were reviewed, with 239 being taken to full text review. Approximately 30 papers are likely to meet inclusion criteria. Preliminary Results indicate that the psycho-social impact is wide ranging, including negative impacts on quality of life, stress, sleep, finances, housing, and family life. Unique outcomes for parents of children with SNI reflect the medical complexity of their children and can also reflect the challenge to get their children's personhood recognised.

Conclusion: There are unique stressors for these families in relation to their child's medical needs that can be helped by co-ordinated, family-centred services.

Relevance for users and families:

This review highlights both common issues for families of children with additional needs such as increased stress and anxiety, and the unique stressors for families where the child has SNI such as learning nursing skills and the difficulty finding information if your child is the only one with their diagnosis in your country. It highlights how important psycho-social support is for these families, and suggests some formal and informal ways of providing this support.

Application of mestinone in a 3-year-old boy with the PURA genetic syndrome

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PURA syndrome is a very rare genetic condition. It is characterized by delayed psychomotor development and reduced muscle tone. About 200 children suffer from PURA, including two diagnosed in Poland. According to current knowledge, the disorders known as PURA syndrome are caused by mutations in the PURA gene, which provides instructions for the production of a protein called Pur-alpha (Purα). Protein performs many important functions in cells, including controls gene activity (gene transcription) and helps copy (replicate) DNA. Purα protein is especially important for proper brain development as it helps to direct the growth and division of nerve cells (neurons). It may also participate in the formation and maturation of myelin, a protective substance that covers the nerves and promotes the efficient transmission of nerve impulses.

methodology

The use of Mestinone administered orally in a 3-year-old boy with PURA syndrome.

Results: Significant improvement of motor functions after 2 weeks of using the preparation

Conclusion: The use of mestinone, previously used in myasthenia gravis, can significantly improve the functioning of patients with PURA syndrome.

We used Mesinon as the second in Europe and the first in Poland.

Relevance for users and families:

Improving the functioning of a patient with a rare disease, which also improves the functioning of the whole family

Case report: Two sisters with Cockayne Syndrome due to ERCC6 variants

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Introduction: Cockayne syndrome (CS) is a progressive, rare autosomal recessive neurodegenerative multisystem disorder. Two causal genes, ERCC6 and ERCC8, were revealed. Patients with CS have various clinical presentation but usually gradually lose skills such as the ability to walk, sit, crawl, talk, hear and swallow.

Patients and methods: We present two sisters with developmental delay, failure to thrive, microcephaly, megacisterna magna and dental anomalies describing the clinical course and process of identifying the genetic disorder.

Results: Older sister was enrolled in rehabilitation according to Stojčević Polovina method because of developmental delay at age of 6 months. She made developmental progress, started to sit and crawl independently. At the age of two years, developmental regression started, mainly in the gross motor development. The diagnostic evaluation (metabolic, brain MRI etc.) did not revealed the etiology of regression. When a very similar developmental problem was recognised in her younger sister, further genetic testing was performed. Clinical exome sequencing in both sisters revealed the presence of compound heterozygous variants in ERCC6 gene, one pathogenic stop gain variant (c.2203C>T (p.Arg735X) and another one, a missense variant (c.2840G>A(p.Arg947 Gln) of uncertain significance. Both parents are the heterozygous carriers. On the basis of the progressive clinical course and familial genetic Results, a diagnosis consistent with ERCC6 related disorder – CS was introduced.

Conclusion: The CS may be difficult to recognize early in life. Establishing an early diagnosis in CS patients is important for determination of rehabilitation goals, life quality improvement and the enabling of genetic counselling.

Relevance for users and families:

Cockayne syndrome is a rare disease that very few medical experts have experience with. It is very important to emphasize that early diagnose is extremely important for families and all members of rehabilitation team, especially now when genetic testing is more available and affordable than before.

Intrathecal baclofen as treatment option for severe dystonia in an eight year old PKAN patient

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Introduction: Generalized dystonia can be a severe symptom of neurodegenerative diseases in childhood. This central movement disorder is often a challenge in management and treatment.

Patients and Methods: We present a 8 year old girl with pantothenate kinase-associated neurodegeneration (PKAN). After a time of constant but slow progression of this neurodegenerative diseases with brain iron accumulation, she developed severe dystonia that repeatedly culminated in dystonic crisis.

She needed extensive oral medication and received multilevel botulinum toxin injections. Despite this medical treatment the severe dystonia and the concomitant vegetative dysregulation could hardly be controlled, especially in times with additional somatic or psychosocial stress.

We then decided upon treatment with intrathecal baclofen to reduce dystonia and pain, as well as ease caregiving.

Results: In neurosurgical intervention the baclofen pump was implanted, with the intrathecal catheter placed at cervical level (C4). After initial effectiveness, the dosage needed to be repeatedly increased over the following weeks to high levels of continuous flow. Frequent interdisciplinary assessment was necessary to adapt the dosage and monitor the treatment Results as well as the side effects. In this process symptomatic interventions for other complaints needed to be considered regularly, as they proved to be relevant trigger factors for the dystonia.

Conclusion: Intrathecal baclofen can be considered in the treatment of generalized dystonia in children with neurodegenerative disease. The effectiveness and dosage in relation to the therapy goals should be monitored individually by clinical experts.

Relevance for users and families:

Although specific diseases might be rare, some symptoms like dystonia can be more common and treatment of this symptoms is a relevant but challenging aim in children with neurodegenerative dieseases

AFOplus - A new, flexible, custom made ankle-foot orthosis for children with cerebral palsy

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Statement of problem: Ankle – foot orthoses (AFOs) are commonly prescribed for children with cerebral palsy (CP). Common types of AFOs are solid (SAFO), hinged (HAFO), dynamic (DAFO), posterior leaf spring (PLS), ground reaction (GRAFO). Due to the variability in AFO design, material and manufacturing as well as CP type, ability and activity level, determining the optimal AFO is a challenging problem.

Description of the product / technology: A new flexible custom made AFO is made of SeaFlex (polyolefin elastomer with three grades of flexibility). Computer Aided Design/Computer Aided Manufacturing technology (CAD/CAM) is used to capture the shape of a child's foot and ankle. The image created is digital and is three-dimensional (3D). Having this accurate image, the practitioner is able to modify and correct the shape electronically, and than send the image to the 3D printer. The orthosis is made according to 3D printed model.

Findings to date: Our findings sugest that AFOplus supports normal joint alignment and mechanics, provides variable range of motion (ROM), facilitates function, stabilises the ankle-foot complex and enables a continuous Achilles-gastrocnemius stretch. Improvements in walking efficiency, and improvements in gait function are also recorded.

Practical applications: AFOplus is designed for children with hemi/diplegic spastic CP (GMFCS I, II, III). It is sutable for children who tend to exibit knee flexion (crouch gate). AFOplus is light, comfortable to wear and well accepted by most of the children. The same AFOplus could be remoulded multiple times during the child's growth, without losing or changing any properties.

Relevance for users and families:

AFOplus is sutable for CP children GMFCS I, II, III.

It can also serve as night splint.

An exploration of the perspectives of paediatric physiotherapists and occupational therapists on the use of custom moulded seating (CMS) systems for children with complex seating needs.

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Introduction: Custom moulded seating is often recommended for children with conditions such as cerebral palsy, GMFCS Levels IV and V, spina bifida, and progressive neuromuscular conditions such as spinal muscular atrophy and muscular dystrophy. The aim of this study is to explore the perspectives of therapists who refer to a specialised seating service on the use of CMS for children, as well as the processes and services involved, including when and why CMS should be considered.

Methods: This study employs qualitative research methodology, using a grounded theory approach, involving focus group interviews with 15 therapists who refer children with complex needs to the Assistive Technology and Specialist Seating Service in the Central Remedial Clinic Dublin.

Results and Conclusions: Therapists shared their views on the many benefits of using custom moulded seating for children with complex needs however they highlighted barriers to ensuring children are provided with this type of seating in a timely manner. This includes access to specialised seating services as well as process and service factors at local, national and specialist seating service level.

Relevance for users and families:

Relevance for families and users: Data obtained from this and subsequent studies will be synthesized to underpin and validate the development of best practice recommendations in relation to the provision of CCS for children presenting with complex seating needs.

Eye-tracking intervention in children with dyskinetic cerebral palsy: goal attainment, communication competencies, and psychosocial impact

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Introduction: Children with severe dyskinetic cerebral palsy (DCP) benefit from eye-tracking technology to access computers for communication, education, and leisure. Eye-tracking skill-acquisition processes are unstructured to date. DCP is a heterogeneous diagnosis and optimizing training programs to fit each person's abilities is challenging. This eye-tracking intervention study explored goal attainment, communication competencies, and the psychosocial impact of eye-tracking in children with DCP.

Patients and Methods: This single case experimental design study included three children with DCP, aged 7-13 years old. The study consisted of four baseline measurements, six-week intensive eye-tracking training of three specifically-tailored goals per participant, and a six-month follow-up. Goal attainment was assessed using the Goal Attainment Scale, communication competencies using the Augmentative and Alternative Communication Profile, and the psychosocial impact using the Psychosocial Impact of Assistive Devices. Descriptive statistics were used to describe any pre-post intervention changes.

Results: Baseline measures were stable for all outcomes. All participants reached their eye-tracking goals post-intervention, two of whom performed much better than expected. Meaningful improvements were found for all participants in their communication competencies, such as operational, linguistic, social, and strategic. Parents reported an overall positive psychosocial impact of eye-tracking, including adaptability and self-esteem. All outcomes were retained at the six-months follow-up.

Conclusions: Eye-tracking training programs with specifically-tailored goals to meet each child's needs and abilities appear to be successful and should be strongly considered in clinical practice to facilitate meaningful skill-acquisition processes that positively impact the use of eye-tracking for activities of daily living, including education, communication, and leisure.

Relevance for users and families:

Not two children with dyskinetic cerebral palsy are the same! Motor and cognitive profiles differ, and their daily needs and interests are unique. This heterogeneity implies that one size does not fit all, particularly when introducing new technologies such as eye-tracking. Our study highlights the critical importance of, first, identifying goals that are unique and meaningful for each child and their family, and second, creating specifically-tailored training programs to successfully reach the identified eye-tracking goals.

Feasibility of an eye-gaze technology intervention for stakeholders to support students with severe physical disabilities and complex communication needs

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Introduction. Eye-gaze technology provides access to control a computer through eye movements and can support participation in curriculum activities, leisure, and communication for students with severe motor disabilities. However, limited studies have investigated whether any challenge exists to its implementation and what practical components to consider when delivering the intervention. This study examines the feasibility for teachers, parents, and therapists as key stakeholders to apply an eye-gaze technology intervention in educational and home environments for students with severe physical disabilities and complex communication needs.

Patients and Methods. This study applied a mixed-method design, focusing on acceptability, demands, implementation, and practicality of the technology intervention. Quantitative data and interviews were collected from sixteen stakeholders of five students who participated in a six-month intervention. The technology intervention included (1) access to eye-gaze devices with individualized computer content and (2) services including training in use, team meetings, and bi-monthly support on pedagogical and technical problems.

Results. The findings showed that the stakeholders perceived eye-gaze technology as appropriate to increase students' autonomy and interaction and enhance understanding of their learning and communication messages. Easy-to-adjust eye-gaze systems and regular support to accommodate the contexts of use were essential. For sustainable implementation, improving assistive technology services was crucial to provide in-service education, team collaboration, and development of a loaning program.

Conclusion. This study contributes knowledge on what key stakeholders considered acceptable in eye-gaze technology intervention. The facilitators and barriers could guide researchers to refine the intervention for further examination of the effectiveness of eye-gaze technology applications.

Relevance for users and families:

This research provides implementation knowledge for parents, teachers, and practitioners to facilitate eye-gaze technology intervention for students with severe physical disabilities and complex communication needs in communication and participation of play and learning.

"The Scanning Pen" Can make wonder in children with Neurodevelopmental disorders

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Introduction: Neuro Developmental Disorders (NDD) are multifaceted condition involving impairments in cognition, behavior, speech language development and motor skills. Researchers have made considerable progress in understanding all types of reading disabilities (Fletcher et al., 2007). For purposes of research, "reading impaired" children may be all those who score below the 30th percentile in basic reading skill. Among all of those poor readers, about 70-80 percent have trouble with accurate and fluent word recognition that originates with weaknesses in phonological processing, often in combination with fluency and comprehension problems. These students have obvious trouble learning sound-symbol correspondence, sounding out words, and spelling.

Scanning Pen is an advanced technological educational device that improves independence and confidence of students while reading.

Patients and Methods: In the current study a sample of 10 children with NDD were selected, age group was from 6-16 years. These children were assessed with Reading Comprehension Assessment Tool before intervention with Scanning pen along with multidisciplinary interventions following Kolkata Developmental Model (KDM). Reassessment was done after three months of intervention.

Results: The findings revealed that essential skills of reading comprehension [phonics, phonemic awareness, vocabulary, reading comprehension and fluency] of those children has improved significantly.

Conclusion: Scanning Pen can be useful assistive device along with multidisciplinary intervention to improve reading comprehension in children with NDD.

Relevance for users and families:

This is a cost effective assistive device which is already evidence based to improve reading comprehension in children with special needs

Psychosocial impact in children using eye-gaze assistive technology in everyday life

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Introduction: Eye gaze assistive technology (EGAT) is a high-tech assistive technology that provides access to the digital world in both play and education. This study investigates the psychosocial impact of eye gaze assistive technology in children with longtime experience of using eye gaze assistive technology in everyday life as well as the psychosocial impact in relation to the duration of use per day.

Participants and Methods: In this descriptive study participated parents of 27 child EGAT users in a structured individual interview using the Psychosocial Impact of Assistive Devices Scale (PIADS). Children were categorised as high, medium or low users of EGAT according to the duration of use per day.

Results: The children's age ranged from 5 – 20 years (M=13), 56% were female and 74% had the diagnosis of Cerebral palsy. EGAT had a positive psychosocial impact on competence, adaptability, and self-esteem among child users. Items with the highest positive scores were Ability to participate and Quality of life. About two third (63%) of the children were low users of EGAT and 15% were categorized as high users. Children's duration of use per day did not impact the perceived positive psychosocial impact.

Conclusion and relevance for users: EGAT had a highly positive impact on the children's participation and quality of life. The study adds new knowledge in that both high and low-duration users scored high positive psychosocial impact of EGAT which is an important message to families and service providers.

Relevance for users and families:

The study adds new knowledge in that both high and low-duration users of Eye gaze assistive technology scored high positive psychosocial impact of the device which is an important message to families and service providers.

An integrated approach for bioinformatics in rare congenital conditions: application to arthrogryposis multiplex congenita

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Introduction: AMC is a term describing multiple congenital contractures, which affects individuals' function and quality of life. Following implementation of an international AMC registry, an integrated approach is adopted for bioinformatics structure and implementation to: 1) Identify characteristics of the data model for an international registry; 2) Identify challenges and mitigation strategies. The EACD-2023 is an excellent platform to share our experience, discuss challenges and mitigation strategies, and contribute to networking in rare congenital conditions.

Methods: Consensus-based dataset was described using a mixed-method study by AMC experts from North America, Europe, and Australia. Human Phenotype Ontology (HPO) was utilized for data linkage. Data structure was developed by the AMC expert panel and experts in computer engineering, software architect, and bioinformatics.

Results: A federated data model of RedCap platforms including 541 data elements for all registry partners are developed and local data sources are identified. HPO codes for 379 (70%) variables were incorporated into the data model to facilitate data linkage.

Conclusion and relevenace: A unified dataset was addressed by adopting the consensus-based dataset as the standard data representation for REDCap data schema. Systematic data discovery and retrieval was ensured by the integrated informatics platform providing a federated view of site-managed REDCap data sources, existing Qualtrics deployments and SQL and MongoDB databases across multiple institutions within the AMC International Consortium, while adhering to local governance requirements. System harmonization with REDCap amongst partners was addressed by a standardized REDCap project schema for data collection, assuring data consistency, validity, and reliability.

Relevance for users and families:

Collection of valid and consistent data promotes knowledge on rare disease management and care.

Joint contractures in an international registry on arthrogryposis multiplex congenita (AMC): From identification to standardization using the Human Phenotype Ontology

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Introduction: Arthrogryposis multiplex congenita (AMC) is a term describing multiple congenital contractures, which affects individuals' function and quality of life. Establishment of an international registry on AMC has prompted this study to 1) identify a consensus-based minimum dataset, and 2) Standardize joint contractures phenotypes to Human Phenotype Ontology (HPO).

Methods: This is a mixed-method study comprised of Focus Group Discussions (FGDs) and 3 rounds of electronic Delphi survey with clinicians, researchers, and adults with AMC. Data elements were identified using a tiered approach by calculating Lawshe's Content Validity Ratio (CVR) > 0.30-0.40 and Fleiss' Kappa (K) statistic > 0.70. Data elements of joint contractures were classified to the HPO according to a validated mapping algorithm.

Results: 541 data elements were identified by specialists in Orthopedics, Occupational/Physical therapy, Medical genetics, Pediatrics, Neurology, Obstetrics/Gynecology, Kinesiology, Epidemiology, and representatives of the AMC community across the United States, Canada, Australia, and Europe. 303 elements for joint contractures were mapped to HPO. Inconsistencies in HPO coding for joint contractures occurred in 57%. A data curation algorithm was developed by multidisciplinary collaborations of 10 specialists in Orthopedics, Pediatrics, Medical Genetics, Obstetrics, and Occupational/Physical therapy across five countries with the HPO team.

Conclusion: International multidisciplinary collaborations was used to provide a basis for AMC knowledge exchange, to promote multi-disciplinary collaborations in rare musculoskeletal conditions, and to empower patients and communities. HPO mapping provided a standardized nomenclature for AMC phenotypes, with substantial improvements in rare disease diagnosis, treatment, and management where multiple joint contractures is the common feature.

Relevance for users and families:

Collection of systematic data improves knowledge in rare outcomes such as AMC, which contributes heavily in improvements in clinical management and care.

Performing together – letting people with motor disabilities play music

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Statement of problem: Musical creation is often limited by an instrument's original design, where a specific motor skill is required . People with motor disorders are therefore less likely to master the instrument and be part of a musical ensemble.

Description of the product or technology: Using a 3D camera, the system can detect the presence of a person within a dedicated area (input). This presence controls the volume of a subpart of a musical track (output). To play the full musical track requires collaboration between the included participants in structuring the dedicated areas.

Findings to date: Initial prototype testing shows a possibility for wheelchair-users to be part of creating music in a social setting, while being entertained. The fact that the users can control music of their own liking makes the system flexible and adaptable for any user.

Practical applications: This new technology enables people with motor disorders to be part of a musical ensemble, by giving all participants equal opportunities to engage in musical creation, in a collective manner. The presented solution is only one way of utilizing low-cost sensors for measuring and analyzing input and translating it to a desired output. Output can be switched on/off for other applications as well, to make it easier for people with disabilities to engage in and control their environment.

Relevance for users and families:

The system can easily be installed, managed and controlled at home, by the user and its family members. Furthermore the equipment is cheap and available to anyone. Finally, the system can be adapted to the users own musical interests.

Moving towards a better understanding of well-being for children with complex disabilities from using the Innowalk

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Introduction: Children with more severe physical disabilities are limited in their ability to participate in physical activities and exercise. It is known that increasing physical activity levels improves well-being across the general population, including children without disabilities. Whether this is so for those children who have mobility limitations and cannot communicate their feelings, is currently unknown. Well-being has different definitions and is especially problematic to measure, for those whose ability to speak is reduced. This research is observing non-ambulant children using the Innowalk, a robotic device, as one context for them to indicate their well-being, to support the development of a new scale.

Patients and Methods: Children aged four to eighteen, with a range of physical and learning disabilities, supported by their parents in a special school context. A consultation group includes two young adults with cerebral palsy.

Exploratory case study series made up of observations (field notes) and parental reported diaries and child/ parent interviews. Preliminary constructs for the proposed well-being scale include calmness, comfort, creativity, energy levels, engagement with other people or activities, expressing joy.

Results: Data is due to be analysed in February-April 2023, using Braun and Clark's six stages of analysis. In addition to academic papers, an accessible booklet will be produced for the participants: 'My well-being stories about the Innowalk'.

Conclusion: The scale developed will potentially enable the content validity to be evaluated in a future larger study to test out the psychometric properties of this proposed well-being scale in wider contexts.

Relevance for users and families:

The well-being of children with complex disabilities is hard to measure. This study will create the constructs that can move understanding of well-being forwards for children with walking and talking limitations. The Innowalk is reported to have health and well-being benefits for non-ambulant people. However, as it is expensive, further evidence is needed to capture some of the subtle, but important effects. These include better sleep patterns and regular bowel movements after using the Innowalk.

Construction and validity of neural network for human physical activity recognition using multiple wearable sensors and deep learning

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Introduction: Self-managed approaches are necessary to support the long term re- and habilitation needs of people with Cerebral Palsy (CP). For health managing- and monitoring purposes, it is therefore important to monitor and quantify physical activity performed by people with CP. We have developed a deep learning network to recognize specific movement classifiers relevant for people with mobility impairments, including CP. The aim of this study is to assess the networks prediction accuracy.

Patients and Methods: 7 sensors provided accelerometer and gyroscope data from 14 healthy adults, performing both scripted as well as free movement while being videotaped. Criterion validity of the network was assessed up against video annotation from two independent annotators. Sensor- and video recordings were done over 5 minutes. Accuracy was used to estimate similarity and diversity between the network and annotations regarding upper- and lower limb activity as well as postures lying, sitting, standing, and walking. 2x2 multilabel confusion matrixes were created to summarize Results.

Results: Overall, annotators agreed by 95% and the network agreed with annotators by 82% accuracy. The network performed best on posture and walking recognition. Most disagreements were found for upper- and lower limb activity, where the network predicted a larger quantity of movement than the annotators.

Conclusion: Valid quantification of real-life physical activity in people with CP, is possible with sensors and our developed network. This is of great value for future home-therapy monitoring, real-time patient feedback, control of therapy interventions, and monitoring behavioral changes throughout CP disability levels.

Relevance for users and families:

Relevance for users and families: The neural network is of great value for future home-therapy compliance monitoring, real-time patient feedback, control of therapy interventions, and monitoring behavioral changes throughout CP disability levels.

Effect of a 14- week Frame Running training program on cardiorespiratory fitness and psychosocial functioning

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Introduction: Frame Running is a relative new para-athletic sports for children and adolescents with a disability. It seems to have the potential to improve cardiorespiratory fitness because high heart rates can be achieved during Frame Running. The purpose of this study is to measure the improvement on cardiorespiratory fitness and psychosocial functioning of a 14-week training program in children with a disability who start Frame Running for the first time. Moreover the intensity of training was evaluated.

Patients and Methods: Until now eight children and adolescents between 6 and 18 years were enrolled in this study. Cardiorespiratory fitness was measured with the Shuttle Frame Running test (SFRT) and 6 minutes Frame Running test (6-min FRT) at baseline and at the end of the training program. Psychosocial functioning was measured with the Kidscreen-27. During each training session a Polar heartrate (HR) monitor was worn to measure training intensity.

Results: At this moment data of three children (3 boys; aged 9, 10 and 17; diagnoses CP [n=1] and Joubert syndrome [n=2]) were analyzed (at EACD 2023 the data of all eight children will be analyzed). The SFRT and 6-min FRT scores improved, with a lower peak HR, suggesting increased fitness. All three participants improved on the Kidscreen-27. On average 76% of training time was spent in the preferred HR intensity 60-100% zone.

Conclusion: These preliminary Results show that Frame Running seems to improve cardiorespiratory fitness and psychosocial functioning in starting adolescents, although more participants are needed for more robust Results.

Relevance for users and families:

This research shows that Frame Running can improve cardiorespiratory fitness and psychosocial functioning in children and adolescents with (severe) disability. These children have very few opportunities to really train and raise their heart rate, and Frame Running is one of those opportunities to be active and participate in sports.

DigiMetku – a digital application for enhancing rehabilitation in everyday life

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Introduction: Rehabilitation often appears as professional-led, system-oriented and fragmented, therefore children and families need a tool that compiles the rehabilitation process, intertwined with the child's developmental environment and daily routines. Rehabilitation may appear to families as a practice in which professionals use different Methods separately from different starting points. The DigiMetku-project develops a digital application that aims to promote the child's functioning in everyday life.

Participants and Methods: The project applies an action research approach, where participants are partner in co-creation. Participants are children undergoing rehabilitation, parents and multidisciplinary professionals invited from the National Association for Pediatric Rehabilitation in Finland. The first step is to develop the content of the application. Next, a web-based application is produced. Finally, the application is piloted and improved based on user experiences.

Results: We present the Results of the design phase describing an overall picture of the digital application's content. Results combine the theories of the child's agency and functioning with the rehabilitation process that actualizes in child's everyday life. Child's rehabilitation process includes identifying meaningful activities, participation and everyday routines, a goal, an action plan, implementation and evaluation. The family-professional collaboration process is structured following the rehabilitation process into the application.

Conclusion: The overall picture of the application's content serves as a common orientation and framework for the co-creation with the developer partners. In this way, good evidence-based rehabilitation practices can be linked to a digital application that families use in everyday life to promote the child's rehabilitation process.

Relevance for users and families:

The application is intended for families and can be used in planning and continuous evaluation of rehabilitation. The application enhances child's functioning by combining the collaborative rehabilitation process in daily life. The application is based on partnership between family and professionals and strengthens engagement and awareness of goal-oriented activities. The findings can be used in comprehensive rehabilitation together with child, parents, the parties planning rehabilitation and persons working with children (e.g. doctors, therapists, education professionals).

Support technology in the rehabilitation process of people with PC

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Cerebral palsy patients have different motor, sensory, cognitive, and communication limitations, affecting their Daily Activity Life in the context of an ever growing technological environment.

The Foundation Aspace Catalunya (Catalunya- SPAIN) wants to show the experience of patients multidisciplinary treatment with high-quality and specialized professionals. Taking into account the patient and family or/and other caregivers as specified by the International Classification of Functioning, Disability, and Health (ICF) according to the needs in the rehabilitation field, adaptative to the own environment and activities. To exemplify, there are 5 cases of patients with Mixed (spastic + dystonic) tetraplegic cerebral palsy that we treated since childhood, GMFGS (Gross Motor Function Classification System) 5, FAC (Functional Ambulation Classification, MACS (The Manual Ability Classification System) 5. This translates into total dependence on DAL and transferences, limitations in communication, and moving.

Our aim was to improve autonomy through the implementation of available strategies with technological tools and solutions for the movement, communication, and environmental control. Using eye tracking access to different complements like the tablet, mobile, devices for communication (emails and social media), control of the wheelchair, and environmental control (home appliances).

Our patients can communicate and drive the wheelchair or control their environment with their eyes, as well as the multimodal intervention model designed to achieve. We want to highlight that a multidisciplinary approach to cerebral palsy patients should include assistive technology as a complementary tool to improve quality of life and autonomy.

Relevance for users and families:

Through five examples, with different degrees of severe functional impairment, we want to give a demonstration (videos and interviews) with tools such as eye reading and programs designed for non-ambulant quadriplegics patients, how we can improve their quality of life and access to other resources that improve their communication and access to the environment, valued by their families and the professionals that work with them

The impact of the exopulse Molliisuit® on functional ability in children with cerebral palsy in Singapore

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Introduction: Spasticity is a common problem in cerebral palsy (CP) that can impact function and affect quality of life (QoL). The Mollisuit® (a suit with embedded electrodes) is designed to reduce spasticity through electrical stimulation of the antagonistic muscles. We aim to evaluate the suit's possible effect on functional ability.

Methods: Recruitment was from January 2021 to January 2022. Individuals aged 4-18 years with spastic CP of GMFCS level I to III were included. Participants wore the Molliisuit® for 60 minutes a day for 4 weeks. Outcome measures included the gross motor function measure-88 (GMFM-88), 10-metre walk test, Goal Attainment Scale and QoL questionnaire (EQ-5D). Assessment was done at pre-, immediately post- and one-month post intervention.

Results: Twenty children, median age 7.0 years old (range 4-16) were recruited. One child with concomitant autistic spectrum disorder dropped out due to intolerability of suit. Descriptive analysis and paired T test were performed on the change in outcomes. Only GMFM Domain C (Crawling and kneeling) scores improved significantly from 88.47±11.42% to 91.73±19.54% (95% CI 0.44-6.07, p = 0.026) after one month use of suit. EQ5D usual activity (child) was also significant (p=0.040). **Results** were no longer significant at 1-month post intervention. Nil major adverse event was reported.

Conclusion: Molliisuit® is a safe alternative therapy that may improve functional ability of children with spastic CP.

Relevance for users and families:

Molliisuit® is a safe alternative therapy that may improve functional ability of children with spastic CP. Further research is warranted to determine the efficacy and benefits of Molliisuit® on pain and gait.

How can we use telerehabilitation to support families of children with disabilities - a qualitative study

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Introduction: The use of technology to promote access to rehabilitation services for children with disabilities has greatly increased over the recent years. However, the intensified use of this intervention modality with children and their families has raised questions about its acceptability.

Patients and Methods: Sixteen parents of children with mild to moderate motor difficulties, who participated in a larger study offering a 12-month access to a telerehabilitation intervention, were purposefully recruited to participate in an individual semi-structured interviews aimed at assessing the acceptability of the multimodal intervention. The intervention included coaching sessions with a rehabilitation professional and access to an online platform (e.g., resources, parent forum). Results were analysed thematically following an iterative inductive-deductive process.

Results: All parents described an overall acceptability and positive attitude toward the telerehabilitation intervention. Perceived effects of the intervention included the evolution of parental skills over the course of the intervention and improvements in the children's functioning Parent's goal-orientated interventions, suitability to families' needs, as well as flexibility of the intervention throughout the year were seen as elements playing a key role in parental acceptability and use of the intervention. Parents' understanding of the goals of the intervention and how it responded to their needs impacted positively their level of acceptance. In addition, the development of a strong relationship between parent and therapist appeared crucial to the sustainability of long-term use.

Conclusion: Using a multimodal web platform intervention to support families with children living with motor difficulties seems acceptable to parents.

Relevance for users and families:

Many parents highlighted that this telerehabilitation intervention was better suited to their family's situation than other interventions experienced before, noting the reduced burden associated with accessing rehabilitation services for their children. Although, appropriateness of telerehabilitation might vary from one family to another, establishing a trust relationship allowing discussion about families' preferences (e.g., needs, daily life routines and rehabilitation goals) to adapt and tailor the intervention could increase acceptability of telerehabilitation.

The role of multisensory integration in the re-habilitation of children with congenital visual impairment

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Introduction: multisensory integration improves the precision of perception and encoding of environmental events, influencing the behavioural response to such events. Sensory modalities are not equally efficient in guiding the perception of different environmental properties. Vision is the most effective sense for the development of many perceptual and cognitive competencies (e.g., spatial representation). Investigating multisensory integration in sensory deprivation would help in understanding its neurobiological mechanisms and developing strategies to train intact senses. Our study aims to evaluate how efficient intact modalities (hearing and touch) are in improving perceptual accuracy in congenital visual impairment (VI).

Patients and Methods: we enrolled thirty-eight sighted and thirty-one visually impaired children aged 6-17. The TechARM, a previously validated device consisting of 5 units providing multimodal stimuli (audio, visual and tactile) and receiving input from the user, was used to provide unimodal (audio or tactile) or bimodal (audio-tactile) stimuli. Participants were asked to touch a unit as soon as they perceived a stimulus and tell how many active units (1-4) they perceived.

Results: from a comparison between accuracy rates in the different stimulation conditions (uni- or bimodal) emerges that the responses to bimodal audio-tactile stimuli are significantly better than responses to unimodal audio stimuli. Furthermore, responses to unimodal tactile stimuli are significantly better than unimodal audio stimuli.

Conclusion: the TechARM is a useful device to quantitatively assess multisensory integration in visually impaired children and adolescents. Moreover, using a multisensory approach in the training of intact sensory modalities would sustain perceptual accuracy.

Relevance for users and families:

Our study demonstrates that the TechARM is an easy-to-use device useful both in the assessment and in the re-habilitation of perceptual competencies in children with sensory disabilities, allowing a personalization of the re-habilitative approach. Moreover, our data expand the knowledge on how multisensory integration develops in the lack of vision and provide further evidence of the importance of a multisensory approach when sustaining visually impaired children' perception and encoding of the surrounding world.

The impact of the Speech Systems Approach on intelligibility for children with cerebral palsy: a secondary analysis

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Introduction: Dysarthria is common in cerebral palsy. The Speech Systems Approach, which teaches children to control breathing and speech rate, has improved intelligibility. We examined if increased intelligibility could be attributed in part to better differentiation of the articulation of individual consonants in single words and connected speech.

Patients and Methods: Forty-two children with cerebral palsy and dysarthria aged 5–18 years, GMFCS I-V, who received the Speech Systems Approach in three published studies. Intervention focussed on production of a strong, clear voice and speaking at a steady rate. Unfamiliar listeners heard recordings of children's speech taken immediately before and after therapy. Outcome measures were listeners' identification of single consonants (e.g. NaP) and clusters of consonants (e.g. STair, eND) at the start and end of words when hearing single words in forced choice tasks and connected speech in free transcription tasks, and acoustic measures of sound intensity and duration.

Results: Listeners correctly identified more word-initial and word-final single consonants and consonant clusters from pre- to post-therapy. Amount of improvement differed across both word position and consonant subtypes. Greater improvement in identification occurred in single words than connected speech. Change in consonant identification varied across children, especially in connected speech. Increases in sound intensity and duration were inconsistent.

Conclusions: The Speech Systems Approach helped children generate greater breath support and speak at a steady rate, leading to more target-like and audible articulations, which helped listeners to identify individual consonant sounds. Transfer of the motor behaviour to connected speech was inconsistent.

Relevance for users and families:

The Speech Systems Approach shows promise in helping children to increase their speech intelligibility and could be tried as part of children's therapy pathway. Children differ in how they achieve clearer speech. We have used the findings to refine the therapy to focus on phrases early in the programme and to personalise instructions to children's individual speech patterns. We are currently testing this personalised approach.

A feasibility randomised controlled trial of an interactive exercise-training device for children with cerebral palsy.

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Introduction: Many children with cerebral palsy undertaking physiotherapy programmes to improve mobility require support to exercise in a functional position. A novel interactive exercise trainer (Happy Rehab™, Innovaid, Denmark) enables children to exercise against resistance whilst standing, but its' efficacy is uncertain. The aim of this study was to explore the feasibility of the ACCEPT randomised controlled trial (RCT) (Registered ISRCTN80878394).

Patients and Methods: Fifteen children with cerebral palsy (gross motor function classification system I-III) were randomised to either 10 weeks of training with Happy Rehab™ or usual physiotherapy. A measure of dynamic balance (Next step test) while stepping and the Pediatric Balance Scale (PBS) were primary outcomes measures, tested at 10 and 20-week follow up.

Results: Twenty-one children were assessed for eligibility, three declined to participate, one withdrew and one did not receive the intervention. Two serious adverse events were recorded. Participants were recruited at a rate of 0.73 per month, limited by the availability of devices. 100% PBS and 87% Next step outcomes were completed at baseline, dropping to 75% and 65% respectively at 10 weeks. The intervention group showed change in PBS of median 2.7 points (interquartile range (IQR) 1) at 10 weeks compared to control group median 1.7 points (IQR 0.67).

Conclusion: The proposed RCT may be feasible with some changes to the protocol and the PBS used as the primary outcome measure.

Relevance for users and families: The intervention was acceptable to children and families, who were willing to accommodate the device for 10 weeks.

Relevance for users and families:

The Happy Rehab interactive gaming exercise device was acceptable to children and families, who were willing to accommodate the device for 10 weeks.

A methodology for spontaneous movements analysis in premature neonates using inertial sensors

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Introduction: This study aims to suggest a methodology for acquiring multimodal information to utilize for early screening of the risk of developmental delay in prematurities.

Methods: The protocol for collecting multimodal information on the spontaneous general movements consists of both the video recording and the motion analysis inertial sensor system at the time of corrected age(CA) 1 month and 3 months. The spontaneous movement for at least 5 minutes is recorded with video camera and audio placed high above the infant. The analysis should be discontinued during prolonged fussing, crying or drowsiness. Using the video, a certified physical therapist performs Prechtl's general movement assessment (GMA) evaluation. Five inertial sensors(Xsens DOT, Netherlands) consisting of 3D gyroscopes, accelerometers and magnetometer are attached to forehead, both wrists and ankles. Data from inertial analysis should be compared to the clinically significant findings including age-specific motor optimality scores of GMA based on the simultaneously recorded video.

Results: The test protocol was completed by a prematurity infant who was born at gestational age(GA) 27+1month with a birth weight of 1100gm and was diagnosed with grade II germinal matrix hemorrhage(GMH). The **Results** showed that the data from inertial motion analysis were sufficiently correlated to the specific findings of GMA. The cramped-synchronized general movement was observed during GMA, which showed correlated vector magnitude and position changes of inertial motion analysis.

Conclusion: This analysis suggests a feasible method for collecting multimodal motion data to develop an artificial intelligence algorithm for the risk evaluation of delayed development.

Relevance for users and families:

There's no relevance for users and families. The authors have no relevant financial or non-financial interests to disclose.

Lessons to learn from adult neurology in the assessment of movement disorders in childhood using wearable sensors: a scoping review

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Introduction: There is large variety in study set-up and protocols quantifying upper limb (UL) movement disorders with wearable sensors, hampering standardization in research and clinics. This review aimed to synthesize sensor protocols and features to quantify UL movement disorders in pathological populations from childhood to adulthood.

Materials/Methods: A literature search using Scopus, Web of Science, and PubMed was performed. Articles needed to meet following criteria: (1) participants were adults/children with a neurological disease, (2) (minimally) one sensor was placed on the UL for evaluation during UL tasks, (3) comparisons between: groups with/without movement disorders, before/after intervention, or sensor features with clinical scales for movement disorder severity assessment. (4) Outcome measures included features from acceleration/angular velocity signals.

Results: 101 articles were included, with the majority Parkinson's studies and only eight studies in childhood populations. Wrist(s), hand and index finger were the most popular sensor locations. Most frequent tasks were: finger-tapping, wrist pro/supination, keeping arms in front of the body and finger-to-nose. Most frequently calculated sensor features were mean, standard-deviation, root-mean-square, ranges, skewness, kurtosis, entropy and dominant frequencies of acceleration/angular velocity signals. Clinical applications were automatization of clinical scales or discrimination between a patient/control group or different patient groups.

Conclusion: Features from one sensor on the hand/wrist or forearm combined with home-based protocols can increase our understanding of the effect of interventions on the severity of movement disorders in Parkinson's Disease. For dystonia and choreoathetosis, one should first focus on adequate sensor features for discrimination between and quantification of both movement disorders.

Relevance for users and families:

We can use current knowledge on the assessment of movement disorders in adults to increase our insights in childhood movement disorders. Standardisation of sensor-setup and protocols and multi-centre studies will be crucial to ascertain sufficiently large sample sizes and to allow home-based or outside-lab assessments.

Relations between brain damage, gait abnormalities, and spinal control in children with cerebral palsy: an explorative study

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Introduction: We explored the relationship between brain damage, gait abnormalities and spinal control (primitive complexes) in children with cerebral palsy (CP) and compared their spinal control with typically-developing (TD) children.

Patients and Methods: A retrospective study was performed, analyzing both brain MR imaging and gait analysis data in children with CP and gait analysis in typically-developing (TD) children. Gait was visually scored and spinal primitive complexes were extracted using non-negative matrix factorization (NMF).

Results: Eighty-four patients were found eligible. Occipital white matter reduction seemed to be related to crouch gait (OR= 12.90 [1.21-137.37], $p<0.05$). No significant relationship was found between other brain damage variables and gait abnormalities, nor did we find a correlation with spinal control (number of primitives). We did find the number of spinal primitive complexes controlling gait to be significantly lower in patients with cerebral palsy as compared to typically-developing children ($p<0.001$).

Conclusion: A relation seems to be present between the amount of damage in the occipital parts of the brain and development of a worse gait type in children with cerebral palsy. No relationship was found between brain damage variables and spinal control. However, in the overall group less spinal primitive complexes were found in CP children, as compared to TD children, which might reflect the lack of gait control due to less cerebral input in children with CP. A prospective study is warranted to elucidate whether other brain damage variables might be informative predictors for gait development as well.

Relevance for users and families:

Finding which types of brain damage are related to certain gait abnormalities and (spinal) control of gait can give us more insights to better patients and their caregivers about future expectations concerning gait development.

First experiments with a multimodal dataset combining affordable wearables and a webcam to report joint angles of daily life activities in the wild

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Introduction: The quantitative evaluation of movement patterns is challenged by its costly priced and the fixed setting of a motion analysis laboratory, hindering the clinical implementation of its relevant data. The advances in computer vision and wearables have put forward the technology that can be used to perform such quantitative kinematic evaluation in the wild.

Patients and Methods: Healthy participants (n=15, 8 female, mean age 30) completed two activities (walking 5 meters back and forth 4 times, and sit and stand 5 times), during simultaneous recording using a commodity webcam and 5 custom-made and affordable inertial measurement units (IMUs). Joint positions were estimated from video using a deep neural network (DeepStream) and joint angles from quaternion data using OpenSim. The knee angle was extracted and kinematics from both approaches were synchronized accordingly.

Results: The median RMSE between the knee angle (degrees) obtained with video and IMU data was 8.79 (IQR 5.36) for walking and 6.96 (IQR 5.66) for sit and stand. In a single camera setting, self-occlusions of body-parts affect detection. IMUs provide useful measurements in three axes, although sensor to segment calibration influences reliability. Notwithstanding, Results are encouraging towards a hybrid approach.

Conclusion: We envision that a multimodal approach to assess lower limb kinematics is feasible combining video and IMUs. Next steps include adding more activities to the dataset and recording children with motor disorders, such as Cerebral Palsy. The long-term goal is using a hybrid system to obtain relevant motion data in the natural environment of the patients.

Relevance for users and families:

The novelty of the dataset is threefold: 1) the selection of movements based on clinical motion assessment scales, 2) the utilization of an affordable system combining a commodity webcam and custom IMU sensors, 3) the implementation of state-of-the-art tools for 3D body pose tracking and 3D motion reconstruction in musculoskeletal models from video and inertial data, respectively.

From marker to markerless: Validating DeepLabCut for 2D sagittal plane gait analysis in adults and newly walking toddlers

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Introduction: The use of 3D marker-based systems is considered the gold standard for tracking limb movements. However, 3D marker-based systems are expensive, limited to laboratory settings, and difficult to apply when studying toddlers. Therefore, in this study, we investigated the validity of a markerless motion tracking software, DeepLabCut, in extracting kinematics from 2D sagittal plane videos of adults and toddlers during walking.

Patients and Methods: Data were obtained from fifteen toddlers performing their first independent steps as well as from sixteen healthy adults. Participants performed both overground and treadmill walking at a comfortable walking pace. Lower-limb gait kinematics computed using a 3D marker-based system (Vicon) were compared to kinematics obtained from DeepLabCut through network training on recorded videos, using two models with either 25% or 75% of the participants as input.

Results: Most notably, the Results were poor for the 25% model, whereas the 75% model showed good (≥0.60) or excellent (≥0.75) intraclass correlation coefficient absolute agreement for most normalized joint angles and clinical parameters. This improvement from the 25% to the 75% model was supported by increased Pearson's correlation coefficients, decreased root-mean squared errors, and increased R^2 values between Methods. Slightly better values were found for adults compared to toddlers as well as treadmill compared to overground walking.

Conclusion: With sufficiently diverse input, DeepLabCut proved a valid tool to acquire gait kinematics in adults and newly walking toddlers. This shows the potential of markerless tracking to study very young typical gait in more natural, out-of-the-lab environments.

Relevance for users and families:

DeepLabCut is an open-source, free-to-download Python package including a GUI tool, which makes it accessible for users with a small budget and little coding experience. Additionally, no markers nor laboratory setting are needed to acquire 2D recorded videos. This makes markerless tracking, compared to 3D marker-based systems, a more widely accessible tool, which allows us to study and thereby improve our understanding of (pathological) gait in the day-to-day life of very young children.

Impaired trunk control in individuals with dyskinetic cerebral palsy is associated with decreased manual ability

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Introduction: Individuals with dyskinetic cerebral palsy (DCP) present with impaired trunk control, assumed to affect upper limb functional activities. However, knowledge on the interaction between trunk kinematics and manual ability is limited. We hypothesized that both position and movement of the trunk during reaching are associated with manual ability.

Patients and Methods: Participants with DCP performed a reach-sideways (RS) and reach-and-grasp-vertically (RGV) task. From 3D motion capture and wearable sensors 22 trunk features were calculated (including active range of motion (RoM), joint angle at point of task achievement, range and peak acceleration and angular velocity in 3D). A univariate linear regression analysis for all trunk features and Manual Ability Classification System (MACS) levels was performed. Subsequently, features showing $p \leq 0.20$ were selected for a multivariate regression using backward stepwise selection.

Results: This study included 22 individuals with DCP (16.11y; STD 5.6y) and MACS levels I-III. Five features reached the $p \leq 0.20$ level for RGV and three for RS. RoM lateral flexion ($B=0.077;p=0.064$) and flexion-extension ($B=0.087;p=0.044$) were included in the final model for RGV. For RS, only RoM lateral flexion ($B=0.079;p=0.081$) was included in the final model. These trunk features explained 39% of the variance in MACS for RGV, and 20% for RS.

Conclusion: Trunk RoM during reaching was associated with manual ability in individuals with DCP. Increased trunk RoM may either impact manual ability directly or is a compensation strategy for impaired upper limb function. Unexpectedly, this relationship was not found within movement related trunk features such as acceleration and angular velocity.

Relevance for users and families:

This study enhances understanding of the trunk-upper limb interaction in DCP and emphasizes the importance of trunk control in upper limb functional activities. Increased insights in the details of this interaction will help to finetune treatment management of the trunk, and thereby will improve functional activities in this population.

Instrumented assessments of bimanual movements in children with Cerebral Palsy: a systematic review

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Introduction: The aim of this review was to report the instrumented assessments (3D motion analysis (3DMA), sensors, etc.) used to evaluate bimanual movements and their metrological properties in children with cerebral palsy (CP).

Patients and Methods: A systematic review was conducted (Prospero CRD42022308517). PubMed, Web of Science, Cochrane and Scopus databases were searched using relevant keywords and inclusion/exclusion criteria. The quality of the articles was evaluated using a customized scale.

Results: In total, 452 children, mostly with unilateral cerebral palsy, mean age 10. 9 (SD 3.2) years, underwent quantitative bimanual assessments in the 31 included studies (mean quality score 22/32 points [SD 4.7]). Five different types of measurement systems were used (3DMA (n=26), accelerometers (n=2), and other instruments (cube, digitizer) (n=3). Children most often performed daily tasks or tasks during a game scenario in laboratory condition. Spatiotemporal characteristics have been extensively studied, including specific bilateral measures (ex: goal synchronization) (n=6). Metrological properties of the protocol/parameters were explored in 22 studies (validity (n=19), reliability (n=2), responsiveness (n=7).

Conclusion: A large number of quantitative bimanual assessments involving different tools, bimanual tasks and specific variables developed to evaluate bimanual function were found. Validation of these tools are needed, especially more metrological evidence on reliability and responsiveness. Future research involving real-life assessments are needed to go further in the exploration of bimanual movements, both to better understand UL impairments and to guide therapies in these children.

Relevance for users and families:

Difficulty executing bimanual tasks is one of the greatest causes of functional impairment for these children because it impacts their participation and quality of life. It would help to identify and further develop the right tool to improve our understanding of bimanual function and to better guide therapies.

VRRS as evaluative tool for upper limb in children with unilateral cerebral palsy

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Introduction: Among the recent technological developments, virtual reality (VR) devices can assist clinicians, offering the possibility to measure motor parameters. VRRS is an innovative VR medical device for (tele-)rehabilitation mainly in adults. This study, supported by the Neuroscience Network for Tele-neurorehabilitation (RIN) Project funded by the Italian Ministry of Health, aims to use VRRS even as an assessment tool for quantifying Upper Limb (UL) movements in children.

Patients and Methods: 12 children with Unilateral Cerebral Palsy (aged 12,19 ± 3,65) were divided into three groups according to the House Functional Classification System (HFCS): HFCS I, grades 7-8; HFCS II, grades 4-6; HFCS III, grades 1-3. All participants carried out clinical (AHA, MA2, BBT) and technological assessment. A 3D exercise was performed by using the VRRS magnetic sensors and kinematics parameters, such as trajectory, time, velocity and jerk, were collected and analysed.

Results: Kruskal-Wallis test followed by post-hoc comparisons showed statistically significant differences for velocity, between groups HFCS I-II ($p<0.001$) and HFCS II-III ($p=0.001$), and jerk for groups HFCS I-II ($p=0.017$) and HFCS I-III ($p=0.030$). Moreover, Spearman correlation analysis reported significant negative correlation between jerk and AHA ($p=0.002$, $\rho = -0.84$), MA2 fluency ($p=0.018$, $\rho= -0.72$) and BBT ($p=0.036$, $\rho= -0.76$) scores.

Conclusion: These promising Results show that children belonging to different HFCS groups differ in velocity and jerk parameters, suggesting distinct UL execution strategies. VRRS could provide a quantitative description of UL functioning, thus, representing a potential evaluative tool to be integrated in the clinical practice.

Relevance for users and families:

This pilot study demonstrates the integration of a technological VR device for the UL evaluation, allowing a complete assessment for the clinicians and at the same time playful and motivating for children. Furthermore, VRRS can also be moved directly to patient's home, by ensuring a quick, effective, and less costly assessment for the family.

A 3D bimanual protocol to detect changes induced by upper limb therapies in children with unilateral Cerebral Palsy

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Introduction: Children with unilateral cerebral palsy (uCP) have motor impairments that negatively impact performance of bimanual activities. The aim of this study was to evaluate the responsiveness of a 3D bimanual protocol, developed to quantitatively assess the impaired upper limb (UL) during bimanual tasks, before and after UL therapies, at an individual and group level.

Patients and Methods: 19 children with uCP, 5-15y, MACS levels I to III, participated in a bimanual intensive therapy during 2 weeks (n = 16) or had UL botulinum toxin injections (n = 4). All children performed the five bimanual tasks of the BE API 2.0 protocol before and after the interventions. The Arm Profile Score (APS), smoothness (SPARC) and trajectory straightness (IOC) were calculated at each visit. A Statistical Parametric Mapping (SPM) was used to analyse movement patterns.

Results: At an individual level, 100% of children had significant changes detected by the BE API protocol on kinematic values (APS, SPARC, IOC). At the group level, children showed significant different movement patterns of shoulder rotation after therapies. Trunk deviations were significantly higher and shoulder plane of elevation was lower after therapies. Smoothness was significantly improved after therapies in one task. No significant differences were found on trajectory straightness.

Conclusion: The BE API 2.0 protocol demonstrated its responsiveness on kinematic parameters of the impaired UL and trunk, especially at the individual level. This objective assessment may offer valid measures, complementary to those obtained with clinical scores, and should be confirmed with a greater sample size.

Relevance for users and families:

Quantitative bimanual assessment could help to improve the understanding of upper limb impairments and to better tailor therapies

Evaluation of postural control in children with movement disorders by means of a new technological assessment tool

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Introduction: Movement Disorders (MD) are characterized by abnormal postures or involuntary movements; thus, the assessment of postural control is crucial for planning the appropriate treatment. Several tools evaluate balance capabilities but, among them, few objectively quantify and recognize the differences among MD patterns. In this study, we propose the Virtual Reality Rehabilitation System (VRRS), as a tool to assess the postural control in children with MD and able to discriminate dystonia, chorea and chorea-dystonia by exploiting its quantitative parameters.

Materials and Methods:Sixteen children (mean age 10.68 ± 3.62 years) with MD were enrolled and tested by using the stabilometric balance platform proper of the VRRS system. All of the subjects were divided into three groups, based on their MD prevalence, and they performed six trials of the VRRS postural assessment. Different parameters related to the movements of the Centre of Pressure (Mean distance, Root Mean Square, Excursion, Mean Velocity, Frequency, Sway Area) were collected from the technological system and analysed.

Results: Results showed significant differences among the three groups of MD in terms of Excursion ($p<.001$), Velocity ($p<.05$) and Frequency ($p<.001$) parameters, pointing out the potential ability of VRRS to detect different type of MD.

Conclusions: The VRRS is a promising technological tool to assess the postural control in children with MD and able to recognize its different pattern in line with the traditional clinical evaluation. This technological evaluation has a great potential in monitoring both the longitudinal clinical follow up and in detecting changes induced by a rehabilitative treatment.

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Relevance for users and families:

The use of VRRS allows us to evaluate children in a playful setting based on the exercise games. A playful-technological approach has a substantial impact on the collaboration and interest of children. Families are curious and proactive regarding the use technological and innovative tools for their children. A deeper knowledge of VRRS, not only in the field of evaluation but also rehabilitation, could have an impact on the creation of a targeted and personalized intervention.

Atypical motor planning in an interpersonal context in 9-year-old children with autism spectrum disorder (ASD)

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Introduction: Motor planning deviances may negatively affect interpersonal motor interactions in ASD, although detailed studies are sparse. This study examined motor planning kinematics in an interpersonal and non-interpersonal context in 9-year-old children with ASD and neurotypical peers.

Patients and Methods: Twelve children with ASD and 17 controls performed two different sequential manual tasks (preferred hand): grasping and placing a peg on a wooden disc (non-interpersonal) or in the hand of an examiner (interpersonal). Three-dimensional kinematic recordings of arm/hand movements were performed. Group and task differences were explored for total movement duration (MD), and for peak velocity (PV) and placement of peak velocity (PPV) during reach-to-grasp and transport-to-place movements, respectively.

Results: Task differences were found in terms of longer MD and higher transport-to-place-PV in the disc- compared to hand-task. An interaction effect was evident for reach-to-grasp-PPV, where the control-group, but not ASD, had earlier reach-to-grasp-PPV and longer relative deceleration in the hand-task compared to the disc-task.

Conclusion: **Results** show that the interpersonal context influenced initial reach-to-grasp motor planning in the control-group, but not the ASD-group. Later in the sequential movement (transport-to-place), the interpersonal context seemed to influence motor planning independent of group. Taken together, this indicates support towards a more careful peg-placing in the interpersonal hand-task in the control-group but much less clearly so in the ASD-group.

Relevance for users and families:

Relevance for users and families: Atypical motor planning may influence motor interaction with peers. Investigations of motor planning and movement organization in ASD could thus inform interventions also targeting interpersonal exchange.

Treatment of Idiopathic Clubfoot Using Botulinum Toxin Type A Injection: A Scoping Review

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Introduction: The Ponseti method, which consists of serial casting, Achilles tenotomy, and bracing, is considered the most effective clubfoot treatment. Studies involving the use of botulinum toxin A (BTX-A) alongside the Ponseti method have been conducted, but no scoping reviews on the topic exist.

Patients and Methods: A comprehensive search was conducted of PubMed, Cochrane, CINAHL, Scopus, and Web of Science according to PRISMA guidelines. Only articles involving the treatment of 3+ pediatric patients with idiopathic clubfoot using BTX-A were included.

Results: Of 6,469 articles generated from the initial search, four met inclusion criteria. 223 total feet (161 total patients) were included, and 144 of these feet were treated with BTX-A injection. The age range of patients was 0-44.6 months. The injection site was the gastrocsoleus muscle complex for all studies, except for one study that also injected the tibialis posterior muscle. Three studies used a BTX-A dose of 10 units/kg and 1 used a dose range of 5-10 units/kg. Primary outcome measures included dorsiflexion with knee in flexion, gastrocsoleus and Achilles tendon length, time in cast for correction, need for Achilles tenotomy, and rate of successful clubfoot correction. Only one study was able to demonstrate that BTX-A improved primary outcomes — the remaining three had mixed or insignificant Results.

Conclusion: BTX-A is a potential non-invasive adjunctive therapy alongside manipulation and casting in idiopathic clubfoot; however, its effectiveness is unclear and should be further studied in clinical trials. Further, there is a lack of standardized outcome measurements in published studies.

Relevance for users and families:

BTX-A injection is a non-invasive therapy that may improve quality of life and outcomes, such as time in cast to correction, in patients with idiopathic clubfoot. If proven effective through more future trials, BTX-A could be implemented as an adjunct to the current Ponseti method of treatment of children with idiopathic clubfeet.

Digital inclusion = social inclusion. Technology is not only about support in rehabilitation for people with intellectual disability.

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Introduction: We live in the 21st century and whether we want to or not, information and communication technology (ICT) is a big part of our lives. To live in diverse and inclusive society we need to think about and work with people with intellectual disability in digital space as well.

Patients and Methods: As a researcher and an educator focused on social and digital inclusion of people with intellectual disability I have varied experience concerning the issue. I am also a part of my own research, which is mostly based on observation is action (research in action). People taking part in this research are people with intellectual disability (children, teenagers and adults) and myself.

Results: To prevent digital exclusion of people with intellectual disability it is necessary to understand what digital inclusion is. This is much more than a computer science lesson. In this presentation I am sharing my experience and approach based on the model of Piotr Plichta model, ICF and F-word for Child Development.

Conclusion: ICT is nothing new. It is so normal for all of us, especially in the post-covid world. Thus, technology is a part of our lives and we need to treat digital inclusion as a natural part of education: formal and informal one. Not being in the digital world is equal to not being fully in the real world. So, the quality of it is significant.

Relevance for users and families:

We talk a lot about technological support in rehabilitation or education for people with intellectual disability. Nowadays technology is an important part of social life - especially adult life. People with intellectual disability create a group at risk of digital exclusion. If we want to talk about social inclusion we have to think about digital inclusion as well. This paper helps answer questions: why is it so important and how to do it well?

How to facilitate a physically active lifestyle with a running frame in children with severe physical disabilities: a qualitative study

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Introduction: Pediatric physical therapists (PPTs) are the designated professionals to facilitate a physically active lifestyle in children with disabilities. Literature shows that PPTs lack effective interventions to increase physical activity levels. A running frame is a novel device that is appealing to children and can support them in engaging in PA and thus has the ability to promote participation.

This study describes which knowledge and skills PPT's need to facilitate a physically active lifestyle with a running frame in children with (severe) physical disabilities.

Participants and Methods: Eighteen semi-structured interviews with PPT's were conducted, recorded and transcribed verbatim. Three researchers independently analyzed the data using an inductive thematic analysis to identify relevant themes.

Results: PPT's had a mean working experience of 29 years (range 3-41 years). Data showed that it is most important that children, parents and PPTs are motivated to use a running frame. PPT's are not always aware of the existence and the possibilities of a frame. Knowledge about how and where to use a frame is crucial. Public (outdoor) spaces must become more accessible for frame users and children need to have their own frame in order to facilitate physical activities in their daily lives.

Conclusion: Increasing motivation to be more physically active by coaching and advising children and their parents during PPT sessions seems important. Knowledge about how and where to use a frame offers new opportunities for PPTs to facilitate a physically active lifestyle in children with (severe) physical disabilities.

Relevance for users and families:

It is very important for children with (severe) physical disabilities and their parents that all PPTs know about the possibilities for using the running frame. The frame can be used during therapy sessions for walking or fitness training. Moreover it can be used for recreation at school or at home, for example playing outside with other children or walking in a park with parents. Children can participate in Frame Running as para-atletic sports.

Does dexamethasone extend postoperative peripheral nerve block analgesia in children undergoing lower extremity orthopedic procedures

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Post operative pain and aniexty are a significant concern, especially in children who undergo multiple procedures, such as children with disabiliites

Peripheral Nerve Blocks (PNBs) are an important postoperative stategy but are limited by pharmacologic half life of the local anesthetics to 8-10hrs

This study evaluates the effectiveness to extend post operative analgesia

IRB approved, double blinded randomized study of 50 consecutive patients undergoing orthopedic lower extremitiy procedures. Goup 1 receive a a PNB with local anesthestic, ie marcaine, mixed with dexamethasone. Group 2 had a PNB with marcaine alone and the dexamethasone was given IV. Pertinent perioperative data was recorded. Linker pain scores were reported by parents and when possible children

23 and 25 children completed the study in goups 1 and 2 respectively. Patient demographics age, weight and procedures were comparable for both groups. 42% of the cases were in children with a developmental disability. 84% of cases involved bony procedure (osteotomies, epihysiodesis, benign tumors) .

Analgesic duration in group 1 was 25.7hrs and in group 2, 22.6hrs but not statistically different

There were no surgical complications and complications from PNB adminstration

90% of parents and 81% of children reported extreme or high satisfaction with pain relief.

Parents reported decreased family disruption as factor for satisfaction

Observations:

1) dexamethasone appears to extend the analgesia effect of PNBs, safely, up 25hrs regardless of route administration

2) parents/ patient report high satisfaction

3) No surgical complications ie infections, wound healing issues or compartment syndrome

Relevance for users and families:

1) dexamethasone ($0.90 US/ 8 miligram vial) can inexpensively and safely extend the analgesia effect of PNBs in children/adolescents undergoing lower extremity bony procedures.

2) Potential for decreased post operative opioid use. This is desirable in children with disabilities who have co-morbidities and frequently take multiple medications

3) allow for recovery at home which is reported as a significant factor to decreased family disruption

The long term Results of combined surgery and robotic rehabilitation treatment in Cerebral Palsy Children - a large cohort prospective study

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Introduction: There is a wide interest in Single Event Multilevel Surgery (SEMLS) and post-operated Robot Assisted Therapy (RAT) in Cerebral Palsy children (CP). The aim was to assess the effectiveness of SEMLS combined with post-op RAT gait and its persistence in 6 months follow-up.

Patients and Methods: 508 CP-patients; age ranges from 5 to 22 years old; 238 operated and 218 non-operated control groups have been included in the study. All underwent one rehabilitation session of 10 days with distal-effectors gait training. For each participant one therapeutic goal was set based on functional tests; GMFM -D, E; GDI; TUG; 6MWT; 10MWT; Goal Attainment Scale (GAS) rating just after intervention (short-FU) and at 6 months (long-FU).

Results: 70,32% obtained the initially established goals of therapy, both surgical and non-surgical, at short-FU and 65,51% at long-FU. There was no difference in GAS rank between operated and non-operated patients. ($p<0,05$) both in short and long-FU. The similar Results were observed for GMFCS and input GMFM score. For non-operated children: the younger (up to 15 y.o) were better therapy responders, achieved their goals faster, the stability of those achievements was stronger ($p<0,01$). The score of short-FU for boys was higher than for girls ($p<0,01$), but the sustainability of the Results was lower ($p<0,05$).

Conclusion: This large cohort prospective study provides the evidence that SEMLS combined with post-op RAT for gait-related purposes is effective for children with CP, with a higher success rate for older than 15 y.o. patients.

Relevance for users and families:

To analyze the surgery's influence on the Results of the rehibilitation process of robotic-assisted physiotherapy for patients with cerebral palsy

Impact of Intraoperative Blood Recovery on Transfusion Rates in Children Undergoing Neuromuscular Hip Reconstructions

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The Transfusion rate in children undergoing neuromuscular hip reconstructive procedures has been report between 25-50%. Allogenic tranfusions are an indenpendent risk factor for perioperative complications. Children with disabilities are have a documented higher perioperative risk due to co-morbidities

This study looks at the effectiveness Intraoperative Blood Recovery (IBR) utilizing a newer, smaller reservoirs (75 and 125cc)

This a subgroup of a larger, retrospective IRB approved review of IBR in children undergoing hip/ thigh surgeries. 19 children who underwent were identified. Pertinent perioperative demographics were collected. Children were assigned to the different bowl size volume based on weight. Primary outcome was the incidence of perioperative transfusions.

17/19 children had a diagnosis of developmental disability. Three of the 19 children received postoperative transfusion (2 children in 75cc bowl and 1 in 125 cc bowl). Overall transfusion rate was 18%. There were no collection or retransfusion reactions. IBR returned approximately 45% of the patients intraoperative blood . Introperative assayed hematocrits of returned blood was 59.5% for 75cc bowl and 65% for 125cc bowl

While this survey has limitations of being a small retropective review it does illustrate:

1) Decreased allogenic transfusion in hip reconstructive procedures(18%) compared to reported literature

2) No IBR related deleterious side-effects, simple to implement

3) Previously unreported hematocrit of returned smaller bowl blood volume to be comparable to published reports of larger, adult size 300cc bowl.

4) Cost of use of IBR in our hospital to be $200/case regardless of blood volume processed

Relevance for users and families:

1) Draws attention to the underutilized use of introperative blood recovery with smaller reservoirs to mitigate the need for allogenic blood transfusionsand the potential for transfusion related complications/diseases

2) Accepted by families on cultural/religious basis as a viable blood conservation strategy

3) Cost effective. Apart from bowls, equipment and personnel likely present in most hospitals

4) Further studies are encouraged

Technology used in assessment or training of task-specific strength and object positioning of the upper limb: a scoping review

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Background: Despite the increase in the development of technology and interactive systems used for the testing and training/rehabilitation for patients and healthy people, an overview of these technologies utilized to assess and train task-specific upper-limb strength and object positioning is still lacking. The aim of this review is to provide an overview of currently available technical systems for assessment and training of the task-specific strength of the upper limbs in humans related to activities of daily life.

Methods: A scoping review was conducted using the following search engines: PubMed, Web of Science and Embase. Articles published up until September 2022 were analysed.

Results: A total of 151 papers were included, and all presented technologies were divided into four domains: camera-based technology, sensor-based system, combination system, and other devices. Different technologies were developed for healthy people and the assessment, testing, and rehabilitation of patients with stroke, spinal cord injury, or other diseases. The most used outcomes in the human upper limbs were muscle strength, range of motion and daily life activity, and scarce technology exists to measure object position.

Conclusion and discussion: This review has shown that different technologies were used in testing and training or rehabilitation of the upper limbs. However, we did not find technology that could measure muscle strength in the upper extremity and object position while performing activity of daily living tasks, especially in children with cerebral palsy. Further studies need to be done on developing a reliable protocol and technology to achieve this.

Relevance for users and families:

NO

Immersed in training – virtual reality as a motivational tool. A virtual reality game designed for children with cerebral palsy.

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Statement of the problem: Motivation is key, for training to be feasible and sustainable. Virtual Reality (VR) is a popular gaming form among children. By using three-dimensional immersive VR headsets (I-VR) the artificial environment becomes so real, that children can fully engage while training physical functions. Previous studies show inconsistent Results regarding the effect of commercial non-immersive VR games such as Nintendo Wii and Playstation. A recent systematic review highlights the need for immersive games specifically designed to meet the demands of therapy programs. Description of the product or technology: We developed a fully immersive and fun VR game that addresses specific therapeutical goals for children with CP aged 6-14 years. The game consists of four virtual worlds and targets function of upper extremities, strength in lower extremities, and balance. It starts with an assessment of the child's physical abilities and the game is then adapted to the individual child. The system consists of a screen (Ipad or TV) and an Oculus Quest 2 headset. Findings to date: A feasibility trial is still ongoing. Preliminary observations show that children are so engaged in the game, that they do not feel like they are training. Families are motivated to play the game at home. The final Results will be presented at the presentation. Practical application: The family may need technical assistance to set up the system. The trial program consists of three 15-min sessions per week during 12 weeks.

Relevance for users and families:

VR is a feasible, motivating, and sustainable way of doing home training. As the game adapts to the physical abilities of the individual child, the child can play and compete on equal terms as his or her typically developed peers or family members. Thereby the child's possibilities for participating in meaningful activities is increased.

Immersed in training – virtual reality as a motivational tool. Feasibility testing of a virtual reality game designed for children with cerebral palsy.

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Introduction: Virtual Reality (VR) has the potential to motivate home training for children with cerebral palsy (CP). Immersive VR (I-VR) makes the three-dimensional artificial environment so real that the child can fully engage while training physical functions. Previous research highlights the need for immersive games specifically designed to meet the demands of therapy programs for children with CP. We have developed a VR-game that is fully immersive and fun, and that addresses specific therapeutical goals. Our aim is to explore feasibility, motivation, and changes in physical ability after applying the game as a home training program.

Materials and Methods: Five children with CP, aged 6-14 with GMFCS and MACS levels I-II participated in a 12-week I-VR home training program targeting strength and balance. The game is adapted to the physical abilities of the individual child. Physical function was tested before and after the intervention. Feasibility and motivation will be explored through interviews with families.

Results: The preliminary Results show that children and parents are motivated to play the game at home. We are still waiting for the post intervention tests, but the final Results will be reported at the presentation, where the game will also be demonstrated.

Conclusion: Preliminary observations show that the children are so engaged in the game that they do not feel like they are training.

Relevance for users and families:

VR is a feasible, motivating, and sustainable way of doing home training. As the game adapts to the physical abilities of the individual child, the child can play and compete on equal terms as his or her typically developed peers or family members. Thereby the child's possibilities for participating in meaningful activities are increased.

RehaBot: A chatbot between therapists and patients to establish telerehabilitation programs and quantify their outcome

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Introduction: Telerehabilitation has become part of our daily treatments, although there lacks a simple, affordable, and organized system that coordinates therapists, children, and parents in the process, while maintaining the social and motivational aspects of in-person rehabilitation. Here, we present an affordable and easy to deploy telerehabilitation system, that includes a chatbot and wearables to serve as an asynchronous communication interface to encourage the family and child to complete a tele-rehabilitation program.

Patients and Methods: The RehaBot is a chatbot integrated in the open-source Telegram instant messenger software and executed on a Raspberry PI affordable computer. RehaBot has two main outcomes: assessment and treatment. RehaBot can collect movement data from commercial wearable sensors (Xsens Dot) or lower-cost custom-made sensors. All data is encrypted and treated according to European data protection regulations.

Results: First, the therapist establishes the therapeutic goals together with the family and child. Based on such objectives, the activities may be chosen from available videos in a database and among custom-made and personalized videos. The child can then chat with RehaBot, that provides instructions and shows the videos in a screen connected to the Raspberry PI. The therapist receives a weekly feedback report on exercise difficulty sensation and data retrieved from the wearable sensors, that can be afterwards employed for reconstruction of the movements on a musculoskeletal model of the patient.

Conclusion: Without replacing in-person treatments, RehaBot has the potential to improve function and boost motivation and adherence, while involving parents, children, and therapists with a common goal.

Relevance for users and families:

We believe that RehaBot has the potential to improve the current tele-rehabiltation approaches as it (1) provides with a personalized exercise program, (2) boosts motivation and adherence to complete the training and (3) enhances the communication between families and users with the therapy-team. The added value of the use of wearable sensors is that a quantification of treatment-derived change can easily inform families and therapists on the next treatment goal.

Does intensity of robot assisted gait training in children with cerebral palsy matter?

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Introduction: Robot assisted gait training (RAGT) is still a rather novel approach for improving gait-related gross motor function of children with cerebral palsy (CP). Few data are available on the optimal intensity and length of program to achieve the improvement in range of movement (ROM) and gross motor function. We wanted to compare outcomes in two training regimes.

Patients and Methods: We retrospectively included data of 114 children with CP (35 female, 11.2±3.6 years, GMFCS I-V) who were referred to intensive inpatient (4-5 sessions/week, 4 weeks; N=88) or less intensive but longer outpatient Lokomat training program (2 sessions/week, 8 weeks; N=26) in last 10 years. Measurements of the passive ROM in lower limbs, Timed up and go test, 10-meters walk test, 6-minute walk test were performed pre- and post-training.

Results: The passive ROM in the knees (popliteal angles) and ankle joints improved significantly in both training programs ($p<0.001$). The proportion of children with hip and knee contractures reduced after RAGT. Significant improvement in walking tests was observed in intensive program group. In the Timed up and go test, the group with the outpatient program also improved significantly ($p=0.031$). The improvement was significantly higher ($p=0.021$ for improvement comparison) than in the group with the intensive program.

Conclusion: RAGT is an effective therapy method in improving the passive ROM in the lower limbs and improving the ability to walk in children with CP. However, none of the programs proved to be more effective.

Relevance for users and families:

Improvement of gait function is an important (re)habilitation goal for children with cerebral palsy and their families. Robot-assisted gait training is one of the efficient Methods to improve passive range of movement in lower limbs and gait function.

Preliminary Results of the gait training with the paediatric exoskeleton ATLAS 2030 in children with Cerebral Palsy and Neuromuscular Disease

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Introduction: it is estimated that over 13 million of children world wide are affected by severe disabilities, and neurological and neuromuscular diseases are a cause of it. One of the most common disabilities that have a negative impact in children's and families' lives is gait impairment. Robotic exoskeletons are a new solution for neurorehabilitation and gait therapy that can help improving children's health status.

Patients and Methods: review and summary of the Results obtained in relation to common effectiveness variables analysed in 1 clinical study with children between ages from 4 to 11, with neuromuscular and neurological diseases, using the exoskeleton twice a week, 1 hour per session, for a use period of 6 months. Muscle strength was assessed with a hand-held dynamometer; respiratory capacity through spirometers; functionality with Gross Motor Function Measure (GMFM-88) for Cerebral Palsy and Hammersmith Functional Motor Scale (HFMS) for neuromuscular disease; quality of life was taken using the KINDL questionnaire.

Results: Muscle strength was mostly improved in hip flexors, knee extensors and ankle dorsiflexors and plantar flexors. Forced vital capacity and forced expiratory volume in 1 second increased. Improvements in functionality were shown in both pathologies as in quality of life in terms of self-esteem, and emotional and physical well-being among others.

Conclusion: The use of ATLAS 2030 paediatric exoskeleton improves muscle strength, respiratory capacity, motor functionality and emotional and physical well-being, in children with neuromuscular and neurological diseases.

Relevance for users and families:

Relevance for users and families: families and children with gait disabilities can access a new technological resource for gait rehabilitation that is proving to be beneficial in aspects related to the physical and psychological health of children with motor impairment.

The effect of overground gait training using wearable exoskeletal robot in children with cerebral palsy: a single-blinded randomized controlled trial

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Introduction: Cerebral palsy(CP) is most common developmental motor disorder in children, causing walking and activity limitation. Robot-assisted gait training(RAGT) using wearable exoskeletal robot can offer intensive overground walking experience. This study investigated the effect of overground RAGT using an untethered torque-assisted wearable exoskeletal robot in children with CP.

Methods: A single blind randomized controlled trial was conducted at 5 rehabilitation institutions in Korea. Nighty children with CP in Gross Motor Function Classification System(GMFCS) level II-IV were randomly assigned to the RAGT and control group. The RAGT group received gait training using torque-assisted wearable exoskeletal robot (Angle legs M20, Angel Robotics, Korea) for 30 min/session, 3 times/week, 6 weeks. The control group received conventional physical therapy (PT) for the same frequency and duration. The primary outcome measure was the Gross Motor Function Measure-88(GMFM-88). Secondary outcome measures included the pediatric balance scale(PBS), selective control assessment of the lower extremity (SCALE), and the Pediatric Evaluation of Disability Inventory-computer adaptive test (PEDI-CAT).

Results: Seventy-eight subjects completed the intervention. In the RAGT group, gross motor functions measured by GMFM-88, responsibility in daily living measured by PEDI-CAT were significantly improved after intervention compared with control group ($p<0.05$). Balance and selective motor control function were significantly improved in both groups without group differences.

Conclusion: Overground RAGT using wearable robot remained superior for improving gross motor function and participation in daily living. This new torque-assisted wearable exoskeletal robot based on assist-as-needed control may effectively complement standard rehabilitation by providing adequate assistance and therapeutic support for children with CP.

Relevance for users and families:

This new torque-assisted wearable exoskeletal robot based on assist-as-needed control may effectively complement standard rehabilitation by providing adequate assistance and therapeutic support for children with CP.

Effectiveness of a home-based Action Observation training in Unilateral Cerebral Palsy: the role of the less-affected hand

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Introduction: Children with Unilateral Cerebral Palsy (UCP) could show, together with an impaired hand function on the more affected hand (MAH), limitations in the less-affected hand (LAH), which may impact overall bimanual skills. In fact, the LAH in children with UCP has often showed to underperform than the dominant hand of typically developing peers.

Among the applications of technology for rehabilitation, the Tele-UPCAT platform (Tele-monitored UPper Limb Children Action Observation Training) allows home treatment based on Action Observation Therapy (AOT), with uni- and bimanual tasks.

Patients and Methods: A waitlist RCT study was conducted (ClinicalTrials.gov: NCT03094455) involving 30 children with UCP (mean age 11.61±3.55 years. The Assisting Hand Assessment (AHA) and the Box and Block Test (BBT) were administered at baseline, immediately after the 3-weeks AOT training or Standard Care (SC) and at 2 and 6 months after the end of AOT training.

Results: data showed a significant difference at the AHA (6.406(2.73) p=0.021) and at the BBT of the LAH (9.826(4.535) p=0.032), which was maintained at all timepoint assessment. We hypothesized that children with UCP may have found a strategy for compensating their difficulties in bimanual tasks due to the MAH, as using the LAH for fostering the integration of the MAH.

Conclusion: This study supports the bimanual content of the rehabilitative goal-directed activities, aiming to a more strategic organization of bimanual function.

Relevance for users and families:

This could drive the rehabilitation content and could increase the awareness of families about the right opportunities and compensations in dailylife.

Feasibility of HABIT-ILE@home for children with cerebral palsy: a pilot study

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Introduction: Children with cerebral palsy (CP) usually have disabilities in voluntary motor control. Hand-Arm Bimanual Intensive Therapy Including Lower Extremities (HABIT-ILE) is an evidence-based therapy including motor skill learning (MSL) principles. Up to now, HABIT-ILE has always been provided during face-to-face group camps. There is a need to ensure a broader access to intensive functional neurorehabilitation. This pilot project investigated whether HABIT-ILE@home, a remote neurorehabilitation, is feasible for children with CP.

Methods: Four children with CP (5-18y) were recruited. They received 15h (5x3h) of HABIT-ILE@home provided by a caregiver with a remote supervision of 30min at the beginning and end of each session. A large touchable screen, the REAtouch® Lite, was used as a support for the therapy. An interview based on a questionnaire (n=68 items, scored from 0 “disagree” to 3 “agree”, a higher rating meaning a more positive aspect of the therapy) was conducted with children and their caregivers after 15h of supervised home-therapy to assess their adherence to the treatment and the feasibility of HABIT-ILE@home.

Results: HABIT-ILE@home included an adequate clinical supervision and HABIT-ILE principles were transferable at patients’ home (mean= 2.5). Caregivers’ adherence was good (mean= 2.4). Even if children’s perseverance remains good (median=2), fatigue may be an obstacle to their involvement in the therapy (median=1.3).

Conclusion: HABIT-ILE@home seems to be feasible for children with CP. It may allow a larger amount of children to benefit from an efficient neurorehabilitation, whatever sanitary conditions or patients’ home geographical locations. Further studies should pay attention to fatigue management.

Relevance for users and families:

HABIT-ILE@home may allow a larger amount of children to benefit from an efficient neurorehabilitation, whatever sanitary conditions or patients’ home geographical locations.

HABIT-ILE@home for children with cerebral palsy: protocol of randomised controlled trials

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"Intensive" interventions applying motor skill learning such as Hand-Arm Bimanual Intensive Therapy Including Lower Extremities (HABIT-ILE) have shown large efficacy in children with cerebral palsy (CP). Nonetheless, as HABIT-ILE interventions are usually proposed as a 2-weeks camp, living in remote areas, having difficulties to travel or specific conditions such as the COVID19 pandemia may become major barriers to benefit from such interventions. Such barriers could be removed by proposing HABIT-ILE at home through a telerehabilitation intervention. The "HABIT-ILE@home" protocol aims at investigating the efficiency of such an intervention in a randomized trial.

Two RCTs are planned with a total of 48 children with bilateral CP (5-18y). The HABIT-ILE@home program will follow HABIT-ILE principles but will take place at home, with the presence of a "caregiver" and a remote trained therapeutic supervision. The HABIT-ILE@home program will include the use of a specifically designed virtual device to ease the application of HABIT-ILE intervention and remote supervision.

A first RCT will investigate the efficacy of an "high dosage" program compared to usual HABIT-ILE day-camp (both 65h/2weeks). Non-inferiority statistical analysis will be used. A second RCT will investigate the efficacy of a HABIT-ILE@home follow-up (45h;1h/d;5d/wk;9wks). Superiority statistical analysis will be used. The primary outcome will be the GMFM-66. Secondary outcomes will include ACTIVLIM-CP, PEDI-CAT, ABILHAND-KIDS, ABILCO, BBT, 6MWT, JTTHF, and COPM.

The Results of this study could confirm the non-inferiority of HABIT-ILE@home in comparison with usual HABIT-ILE. Moreover, the changes induce by the therapy, both modalities, could be improved by the HABIT-ILE@Home follow-up.

Relevance for users and families:

For the first RCT, if a HABIT-ILE@home program shows similar effectiveness as HABIT-ILE in a day-camp setting, this would allow more children to benefit from evidence-based neurorehabilitation. Concerning the follow-up RCT, if a specific HABIT-ILE@home follow-up shows greater efficacy than a usual care follow-up, this would give greater opportunities to maintain and potentialize the improvements after a high-dosage HABIT-ILE program.

HABIT-ILE at home for children with cerebral palsy: a pilot study

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Intensive interventions, based on the principles of motor skill learning, have demonstrated excellent effectiveness in improving motor function and daily life independence of children with cerebral palsy (CP). Patients living far from big cities do not have easy access to such interventions, usually applied in the form of camps. This study aims to test a home version of Hand-Arm Bimanual Therapy Including Lower Extremities (HABIT-ILE), with the use of a specifically designed virtual device and a remote supervision.

Four children with bilateral CP had a 15h individualized HABIT-ILE@home program (3h/d, 5 days) provided by a caregiver (relative), remotely supervised by trained therapists (2x30min/d). Each participant received a virtual device (REAtouch®Lite) designed for allowing remote supervision and ease the application of HABIT-ILE at home. Children had two testing sessions, before and after the one-week intervention. We used the COPM to set functional goals and measures goals attainment and satisfaction (2 goals/child). We also used the GMFM-66 and the Box & Blocks test (BBT) for motor function outcomes, and self-reported daily activities questionnaires.

Significant increased scores were observed for the COPM (performance p=0,03; satisfaction p<0,001), and GMFM (p=0,02). Non-significant Results were observed on the BBT and daily activities questionnaires (all p>0.05).

Overall the patients' scores increased, with significant changes in functional goals and gross motor abilities. We can hypothesize a larger amount of therapy would have led to significant improvements. With maybe, similar changes than in a usual evidence-based HABIT-ILE day-camp interventions.

Relevance for users and families:

This totally new approach of HABIT-ILE intervention showed promising preliminary Results and deserves to be further investigated. Along with the use of a specifically designed virtual device and a trained remote supervision, this would provide a practical, innovative approach of intensive rehabilitation for families who do not have access to intensive rehabilitation camps.

The effect of whole body vibration therapy on children with cerebral palsy: a systematic review

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Introduction: Whole body vibration therapy is an intervention modality in which mechanical stimuli (oscillations) are delivered to the entire body from a platform. Cerebral palsy is one of the leading causes of disability in childhood that affects movement, balance, speech and cognitive development. The aim of this systematic review is to appraise the current up-to-date evidence on the effect of whole body vibration therapy on patients with cerebral palsy.

Patients and Methods: Medline/Pubmed, Embase, Cochrane library, Google Scholar databases were searched by keywords “whole body vibration” and “cerebral palsy” on November 2022 and included articles were screened using PRISMA guidelines. The quality of studies was assessed using the PEDro scale.

Results: Fifteen articles met inclusion criteria. The Results revealed that whole body vibration therapy Results in reduced spasticity in upper and lower extremities, especially in decreased spasticity of knee flexors, knee extensors, m. soleus; increased strength of knee extensors and flexors, m. tibiais anterior; improved walking speed; ambulatory function; sitting ability and balance.

Conclusion: Whole body vibration therapy can be used as an auxiliary noninvasive and nonpharmacological treatment method to reduce spasticity in children with cerebral palsy, improve lower extremity muscle strength, walking speed, ambulatory function, sitting ability and balance.

Further high quality studies are needed to determine the long-term effect of whole body vibration therapy on children with cerebral palsy.

Relevance for users and families:

This systematic review may help to make informed decision whether to use whole body vibration therapy to reduce spasticity in children with cerebral palsy.

Fidelity Measures of Job Coaching Interventions that Support Autistic Youth and Adults in Paid Integrated Employment: A Narrative Review

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Introduction: Job coaching (JC) provides support to autistic individuals in paid employment, and little is known about evaluating its fidelity. This narrative review examined the characteristics of JC fidelity tools in paid, integrated employment programs for autistic individuals without intellectual disabilities.

Patients and methods: CINAHL, Medline, PsycInfo, Embase, Emcare, and Business Source Premier were searched, followed by a title/abstract, and full-text screening to identify JC fidelity tools within studies. Studies included participants: (1) with an autism diagnosis; (2) age >16 years; (3) with an Intelligence Quotient >70; (4) in paid, integrated employment; and (5) had received JC.

Results: Four studies met the inclusion criteria. Four fidelity checklists were identified. The studies assessed technology-assisted JC for individuals over the age of 18 years. Included tools were categorized using the National Institutes of Health Behavior Change Consortium's model for Treatment Fidelity. Using this model, all studies described coaching, three studies measured the employee's understanding, and two studies outlined job coach training, and assessed employee's enactment of skills. Most fidelity checklists described how to support an employee, the type of prompts/praise delivered, and how to customize the intervention based on the employee's needs.

Conclusion: This study describes existing JC fidelity tools within a paid employment context and highlights the technological approaches to supporting JC for autistic individuals. Implications of this work will be discussed to explore the application of fidelity tools in community-based employment programs for autistic youth and adults to increase consistent evaluation of JC implementation and improve program outcomes.

Relevance for users and families:

Autistic individuals without an intellectual disability face high unemployment rates. Many, 16 years and older, receive vocational rehabilitation services to attain and maintain paid, integrated employment. Job coaching helps autistic individuals maintain employment. Technology-assisted job coaching can assist in reducing barriers within paid employment. Examining whether these interventions were delivered as intended using fidelity tools can allow for a job coaching intervention to be accurately and consistently replicated within the community, in diverse settings.

Children with Cerebral Palsy Improve Affect Recognition After Completing a Home-Based Computerized Cognitive Intervention

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Introduction: Children with cerebral palsy (CP) have emotion recognition and regulation difficulties which could impact their daily life. This study aims to test the efficacy of a home-based computerized cognitive intervention on affect recognition in children with CP.

Patients and Methods: Sixty participants (30 females) with CP (8-12 years old) were paired by age, sex, motor ability (MACs I-III), and intelligence quotient (IQ 75-126), then randomized to intervention/waitlist control groups. The intervention group undertook a 12 week home-based computerized cognitive intervention programme (5 days/week, 30 minutes/day, total dose 30 hours). Affect recognition was assessed using the Affect Recognition subtest from the Developmental NEuroPSYchological Assessment-II (NEPSY-II). Assessments were performed at baseline, immediately after, and 9 months after completing the training. Affect recognition differences between groups were examined using analysis of covariance, including pre-training performance as a covariate.

Results: In the intervention group, 17% (n=5) of participants showed affect recognition impairments at baseline assessment. Immediately after the program the intervention group presented with significantly better performance (F=6.9, p=.011, n_p^2 =.126) compared to the waitlist control group. These improvements were maintained 9 months after intervention (F=4.5, p=.039, n_p^2 =.074). Among the participants in the intervention group with affect recognition impairments in baseline, 40% (n=2) showed normal affect recognition functioning immediately and 9 months after the intervention.

Conclusions: A home-based computerized cognitive intervention improves affect recognition in children with CP. Our findings highlight that including affect recognition tasks in cognitive interventions for children with CP can result in short- and long-term positive effects.

Relevance for users and families:

The study proves that affect recognition tasks included in executive functions computerized intervention can improve this part of social cognition in children with cerebral palsy.

Can children be motivated to perform physical therapy exercises at home through "serious gaming"? A study on the feasibility and acceptance of teletherapy in children with central movement disorders

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Introduction: Therapeutic computer games, so-called "serious games", have good efficacy in children with cerebral palsy according to a review paper by Chen et al. For our study, we evaluated for the first time a commercially available serious gaming system for home and teletherapy.

Patients and Methods: Controlled, randomized clinical pilot study on the feasibility and effectiveness of the therapy system. To assess the feasibility, the parents of the patients answered a standardized questionnaire. 8 questions are answered from 0 (negative assessment) to 10 (positive assessment) and are expressed in rounded mean values.

Results:

- 29 data sets were fully evaluable:
- Feasibility at home was rated as "good" (Mean 8.8/10).
- Most parents would repeat the therapy (Mean 8.3/10).
- The therapeutic supervision by means of online video monitoring was perceived as "rather helpful" (Mean 8.3/10).
- The usability of the serious gaming system was "rather intuitive" (Mean 7.6/10).
- Parents would recommend the therapy to others (Mean 8.7/10).

Conclusion: The parent survey data presented here demonstrate the feasibility and acceptability of serious gaming in the home setting.

Tele-therapy at home using "serious games" and therapeutic supervision has been shown to be mature in this pilot study, according to initial subjective and objective observations. In times of the corona pandemic, but also beyond, tele-therapy as a therapy concept for the home represents a real complement to conventional therapies.

Relevance for users and families:

Home and teletherapy through serious games offers many advantages:

Main advantage is a greater motivation to do exercises at home. Moreover, exercises can be guided and monitored at home. This eliminates unnecessary trips to therapists and children in remote locations can be better cared for.

Our study shows that the technology is ready and this would already be a good therapy supplement for many children.

Comparison of Hand Robotic Therapy and Occupational Therapy in Children with Hemiparesis

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Introduction: robotic therapy within a pediatric population can improve motivation and attention while focusing on the practice of a difficult motor task. Hemiparesis in children is mostly the result of unilateral spastic cerebral palsy. Active practice, with sufficient repetition and skill progression, is essential to induce neuroplastic changes within the motor system.

Methods: fifty-two children (4 – 19 years, mean age 7) completed participation in this prospective study. 40 children had cerebral palsy, 7 brachial plexus paresis, one CVI, MND II, malformation syndrome, muscle dystrophy and spinocerebellar ataxia. Participants underwent clinical assessments using Box and Blocks Test (BBT), Nine-Hole Peg Test (9HPT), Action Research Arm Test (ARAT) and Quality of Upper Extremity Skills Test (QUEST) at baseline and after completion of therapies. All patients received 7 weeks of medical exercise and robotic therapy with Armeo. Patients were divided into two groups: one group (26) additionally had Amadeo robotic therapy while the other (26) had occupational therapy.

Results: there were no statistically significant differences between the groups in: gender, age, level of impairment (for cerebral palsy GMFCS, BFMF, MACS), spasm, $p>0,05$. All applied clinical tests improved in both groups: BBT $p<0.001$, 9HPT $p<0.001$, ARAT $p=0.011$, QUEST overall $p<0.001$, dissociated movement domain $p=0.001$, grasp $p=0.011$, weight bearing $p=0.001$ and protective extension $p=0.046$. Groups differentiated in frequency of arrivals: Amadeo group median of arrivals 20.5 vs occupational therapy 36.0 days, $p=0.014$.

Conclusion: robotic hand therapy with Amadeo for the same level of improvement reduces the frequency of arrivals to therapies for 15.5 days.

Relevance for users and families:

The use of robotic devices to augment traditional therapy can provide reliable, reproducible and highly motivated exercise. The amount and type of practice a learner receives, how practice relates to the acquisition of a novel task or skill, and improvement of skilled performance are the key elements to know when applying robotic therapy. This study solves the organisational issue of therapy arrivals' frequency.

Walk this way: Development of the walk-along interview method for children with cerebral palsy

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Introduction: Children with cerebral palsy (cwCP) fall often, but causes of falls are not well understood(Boyer and Patterson, 2018). Stability is typically assessed while walking on level-ground and does not reflect how cwCP lose their balance in challenging environments(Malone et al., 2015). Walk-along interviews are a way of discussing daily experiences while walking(Carpiano, 2009) and can generate rich data with children(Ergler et al., 2021). Thus, listening to cwCP talk about challenging environments while walking may provide greater insight into daily fall experiences. This abstract presents the design and development of walk along interviews with cwCP.

Patients and Methods: Over 6 weeks, 8 cwCP (8-17 years old) and 6 parents engaged in public involvement conversations and activities to co-design a walk-along interview protocol(Walker et al., 2021). This resulted in creating pre-planned walking routes around each child's local area and a map of the walk-along route provided to participants.

Results: Eleven walk-along interviews have been completed so far. During each walk-along interview (~25 minutes in duration) cwCP and parents discussed everyday 'challenging' environments (likely to cause a fall). Chest mounted cameras (Kaiser Baas X450) and wireless microphones (RODE GO II) were used during interviews to capture environments and conversations. Data from microphones were synchronised, matched to video footage, manually transcribed and analysed in NVivo using interpretive description(Thorne, 2016) to identify key themes.

Conclusions: Our walk-along protocol can capture detailed conversations about how falls may occur in previously unknown challenging environments. Data analysis currently demonstrates initial success for exploring meaningful experiences of cwCP.

Relevance for users and families:

Our walk-along protocol offers a unique way of exploring lived experiences of where and how everyday falls occur for cwCP. The protocol allows children's thoughts and experiences to be acknowledged and inform future work looking towards treatment and diagnoses for fall prevention. We offer insight into how the walk-along protocol has been successfully developed with cwCP.

Lived experience among parents of the phenomenon physical activity, enabled through a novel dynamic standing device for nonambulant children with cerebral palsy

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Introduction: Children with cerebral palsy who are nonambulant face challenges in finding physical activities. Dynamic standing exercise in a novel motorized assistive device (Innowalk, Norway) has shown positive effects for nonambulant children including being a physical activity. As children with severe impairments need support for physical activity, the aim of this study was to explore the lived experience of physical activity for parents themselves and for their children who are nonambulant.

Patients and Methods: Eleven parents to children, who participated in a study on exercise effects from dynamic standing for nonambulant children with cerebral palsy, participated in interviews. A descriptive inductive design with a hermeneutic phenomenological approach was used for the analysis.

Results: The parents experienced being physically active as important but difficult, especially for their child, as described in theme 1 “Being aware of health benefits while struggling with family time”. The child was perceived as being dependent on people, environment, and equipment for participating in physical activity, referring to theme 2 “Being dependent”. Getting the opportunity for their child to become physically active on regular basis through an assistive device meant hope for a better life, which formed theme 3 “Getting hope in a hopeless life situation”.

Conclusion: The right people, environment and assistive devices are crucial for getting a better life through regular physical activity. When these different variables function well, the parents experience hope for the future.

Relevance for users and families:

Being physically active on regular basis through support of people, environment and an assistive device enabling tailored exercise implies many health benefits for nonambulant children throughout the life span.

Investigating parent carer and allied health professional perspectives on the use of telehealth for disabled children and young people during the COVID-19 pandemic

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Introduction: The onset of the COVID-19 pandemic led to a rapid uptake of telehealth to allow for continuity of care. The parent carer and allied health professional perspectives on telehealth were explored to understand factors that facilitated and hindered the implementation of telehealth in an emergency and its sustained use.

Patients and Methods: Thirty allied health professionals and 46 parent carers took part in semi-structured interviews or focus groups about service changes during the COVID-19 pandemic. Thematic analysis was carried out on extracts describing the experience of telehealth from a wider dataset of transcripts.

Results: Telehealth was implemented rapidly. Parent carers and allied health professionals described telehealth as less effective for the delivery of therapies compared to in person appointments. Challenges to the delivery of telehealth included lack of connectivity, lack of or unfamiliarity with technology, disengagement of children and young people, and increased preparation for sessions. Telehealth was suited to providing advice and follow up on delivered programmes/interventions, but the lack of physical contact impacted assessment and management of care. Telehealth provided flexibility in delivery of services, brought greater understanding of family situations and increased communication between professionals and families.

Conclusions: While telehealth helped fill a gap during the pandemic, its continued use for delivering allied health services requires strategic planning. Both professionals and families require training in telehealth. Investment and research are needed to improve the effectiveness and acceptability of telehealth for allied health led care and to understand for which interventions and families telehealth works well.

Relevance for users and families:

As COVID-19 restrictions reduce globally, services are looking at which service changes should be continued beyond an emergency response. One such change is the increased use of telehealth for service delivery. Given the challenges in adapting allied health interventions to telehealth during the pandemic, this paper provides insights into what can facilitate or hinder the successful implementation of telehealth into service delivery for both the professionals delivering therapies and the families receiving them.

Development of Novel Dysphagia Evaluation via Video Analysis Based on Deep Learning Method in Neonates and Infants: A Preliminary study

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Introduction: Neonatal Oral-Motor Assessment Scale (NOMAS) is a swallowing disorder evaluation method applicable to infants under 48 weeks of post menstrual age. Based on NOMAS evaluation, this study aims to explores the possibility of developing a novel dysphagia evaluation method with deep learning based artificial intelligence (AI).

Methods: This study was conducted on infants under 2 months of correction age, clinically suspected dysphagia. After taking a video of a bottle feeding, the section of footage where the abnormality on NOMAS evaluation was most prominent was selected. Then anatomical structures related to swallowing were mapped in each frame, and deep learning-based video analysis was performed to analyze the correlation between this result and abnormality in NOMAS evaluation.

Results: Two infants with clinically suspected dysphagia were included in this study. The first case was evaluated as dysfunction in the NOMAS evaluation for excessive-wide excursion of jaw was observed. Three vertices of the edge of lips were mapped, and deep learning-based analysis confirmed that the area of triangle formed by three vertices was relatively larger. The second case was evaluated as dysfunction in the NOMAS evaluation, because when sucking bottle, jaw rises faster than it descends, suggesting tongue retraction and minimal excursion of jaw. When this section was analyzed by deep-learning AI, the time taken for upward action of chin was shorter than the one for downward action.

Conclusion: By Deep learning-based AI analysis through recording and mapping of bottle-feeding video, it was possible to obtain correlating data to evaluation items of NOMAS.

Relevance for users and families:

There's no relevance for users and families. The authors have no relevant financial or non-financial interests to disclose.

The relation between proprioceptive deficits and perceived bimanual performance in children with unilateral cerebral palsy

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Introduction: Proprioception is the ability to perceive our limb position in space and is crucial for the performance of daily life activities (ADL). Hence, proprioceptive deficits, which are present in both upper limbs of children with unilateral cerebral palsy (uCP), can hinder the smooth performance of ADL. Here, we investigated the relation between proximal and distal proprioception of the upper limbs with ADL-performance in children with uCP.

Patients and Methods: Thirty-nine children with uCP (age=11y5±2y11m, Manual Ability Classification System: I=23, II=12, III=4) participated. Proximal proprioceptive deficits were quantified using a contralateral position matching task on the Kinarm exoskeleton robot. Distal proprioception was measured using an active and passive position sense task on the ETH Mike robot without vision. In the active task, children moved their finger to an indicated location, while in the passive task, children specified the perceived finger location on a screen above the hand. The Children's Hand Use Experience Questionnaire (CHEQ) was administered to score perceived performance in daily life. We calculated Spearman correlation coefficients (r) between proprioception and ADL-performance.

Results: For the non-dominant upper limb, children with increased deficits in proximal (r=-0.33-(-0.49); $p<0.05$) or distal proprioception (r=-0.33-(-0.50); $p<0.04$) showed lower scores for ADL-performance. For the dominant upper limb, only proximal proprioceptive deficits (r=-0.31-(-0.53); $p<0.01$) were related to decreased ADL-performance.

Conclusions: Children with uCP with increased proprioceptive deficits of both the non-dominant and dominant upper limb perceive more difficulties with ADL-performance. These findings underline the relevance to quantify proprioception of both upper limbs in children with uCP.

Relevance for users and families:

Previous studies have reported impairments in the dominant and non-dominant upper limb in children with unilateral cerebral palsy compared to typically developing children, despite the unilateral diagnosis. Our Results further indicate that the proprioceptive impairments of both upper limbs may contribute to a decreased performance of daily life activities. Hence, our findings underline the importance to quantify proprioception of both upper limbs in children with unilateral cerebral palsy.

Motor performance of children with cerebral palsy during the interaction with robot

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Introduction: Different agents, techniques, and recently different types of robots are used in the treatment of children with cerebral palsy. Today, with the development of technology social robots could be used during habilitation of children with cerebral palsy. The aim of this research was to evaluate the motor performance of children with cerebral palsy after interacting with the social assistive robot - Marko (Mobile Anthropomorphic Robot of Cognitive Traits).

Patients and Methods: The research was retrospective, by reviewing videos recorded during the children's sessions with the robot at the Clinic for Children's Rehabilitation in Novi Sad. Eight children with cerebral palsy participated in the research. There were five boys and three girls. The average age of the participants was 9.21 years. Of the eight children with cerebral palsy, four also had mental retardation. We used evaluation according to the grading system described in the article of Fridrin M. and Belkopoyatova M .

Results: In the first session, there is no statistically significant difference in the performance of motor actions between children who have cerebral palsy and mental retardation and children who have cerebral palsy without mental retardation. During the second session success in motor performance in whole group was lower (90.62% vs 81.94%). Children who have mental retardation perform worse motor performance. (74.07% vs 86.57%).

Conclusion: The motivation of children with mental retardation decreased during second session, but the rest of the group still shows satisfactory motivation while practicing with the robot.

Relevance for users and families:

The Introduction of robots into the process of children's rehabilitation can help with motivation during exercise, especially in children without mental retardation. Parents had a positive opinion about the Introduction of the robot during therapy.

Validity of the UK-CBiLLT, a computerised assessment of children's spoken language comprehension

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Introduction: The C-BiLLT, validated originally in Dutch, is an online spoken language comprehension assessment children that complete using their usual access Methods. The C-BiLLT was translated into British English. Images for 12/82 items were changed to ensure familiarity to UK children. This study examines the validity of the UK-C-BILLT.

Patients and Methods: 480 typically developing children from North East England aged 1:06–7:05 years; 40 per six month age band. Children complete the UK C-BiLLT, Pre-School Language Scales 5 UK Edition (PLS5), and either the visual reception scale of the Mullen Scales of Early Learning ((MSEL) children aged 18-65 months) or the Ravens Coloured Progressive Matrices ((CPM) 66-89 months). Convergent validity (UK-BiLLT vs PLS5) and divergent validity (UK C-BiLLT vs MSEL/CPM) are assessed using correlations. Test-retest reliability (n=48) is assessed using intra-class correlations and internal consistency using Cronbach's alpha.

Results: 202 children recruited to date; currently consenting others in schools and nurseries. Data collection due for completion by 1/3/2023. Interim assessment shows strong correlation between UK-C-BiLLT and PLS5 r 0.78 ($p < 0.001$) and moderate correlations between UK-C-BiLLT and MSEL r 0.59 ($p < 0.001$) and UK-C-BiLLT and CPM r 0.41 ($p = 0.002$).

Conclusion: UK-C-BiLLT shows strong construct validity. We will report convergent and divergent validity for the full sample, internal consistency of the measure and test-retest reliability.

Relevance for users and families:

UK-C-BiLLT will enable accurate assessment of the language comprehension of young children with severe motor and speech difficulties. Responses can be used to ensure appropriate goal and intervention planning.

A maternal refugee life experience has negative effects on the neurodevelopment and behavioural status of the offspring shortly after birth: cross-sectional clinical case study

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Introduction: Maternal stress during pregnancy may impair infant`s neurodevelopment. Being a refugee may be considered stressful. This study evaluated whether potential maternal anxiety and depression in refugee (Syrian) and non-refugee mothers (Turkish) were associated with less favourable neonatal motor behaviour.

Patients and Methods: Turkish (n=64) and Syrian (n=17) term-born infants (370-416 weeks' gestation) were assessed shortly after birth (median 5 days (IQR 4-6 days)) together with their mothers. General Movements Assessment (GMA) was used to determine neurodevelopmental risk; and the Test of Infant Motor Performance (TIMP) to evaluate motor performance and stability of behavioural state. Mothers completed Beck Anxiety and Beck Depression Inventories in native languages.

Results: Perinatal, social characteristics and GMA ratings of both groups were similar with definitely abnormal GMs occurring in five Turkish infants (8%) and one Syrian infant (7%). TIMP scores of Syrian infants were significantly lower (45.53 (SD 7.099) vs. 51.59 (SD 8.593), respectively (p= 0.009)) and more Syrian infants cried at TIMP assessment's end (29% vs. 8%; p=0.030) than Turkish infants. Syrian mothers reported significantly less anxiety (0 [IQR 0-1.5] vs 1 [IQR 0-5]; p=0.024) and depression (0 [IQR 0-4.5] vs 2.5 [IQR 0-7]; p=0.046) than Turkish mothers did. Maternal anxiety and depression scores were not significantly associated with TIMP-scores (ρ=0.165, p=0.141) and ρ=0.150, p=0.181).

Conclusion: Maternal refugee status was associated with less favourable neonatal motor performance. The latter was not associated with maternal reports of anxiety and depression. It might be that the Beck questionnaires had not caught stress associated with refugee status.

Relevance for users and families:

This study indicated that newborn infants of Syrian refugee mothers had less favourable motor performance than neonates born to non-refugee Turkish mothers. This difference could not be attributed to maternal anxiety or depression. Nonetheless, the study suggests that motor development of babies born to refugee mothers should be carefully monitored.

The Pediatric Physical Therapist in a new era of Patient Centered Care in the Netherlands

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Introduction: Patient relevant outcomes and scientific research are the basis of shared decision making and change the clinical practice of pediatric physical therapy. The Dutch Society for Pediatric Physical Therapy (NVFK) is developing a program to contribute to the vision that "in 2040 Dutch children, with and without a chronic disease or disability, are the healthiest children in the world".

Objectives: To gain insight in needs and expectations of Dutch PPT's regarding their future role and to gather support for the vision, a survey has been conducted.

Methods: One hundred and eighty PPT's were involved. Questionnaires (n=43) and semi-structured interviews were conducted (n=27). Colleagues (n=30) participated in groups and semi-structured interviews. In digital co-creation sessions with researchers (n=20) and PPT's (n=60) outcomes were discussed.

Results: The Results were clustered: (1) working in child's environment, (2) strengthening regional networks, (3) focusing on coaching children and parents, (4) strengthening interdisciplinary collaborations, (5) creating a platform to connect and educate, (6) focusing on prevention, (7) clear definition of the role of PPT's, (8) integrating science in practical skills (9) integrating measurement protocols in practice and (10) suitable financial support. Bringing researchers and PPT's together proved to be successful and an inspiring experience. Increased connection with the professional community was reported.

Conclusion: Creating a joined vision on the PPT perspective in the changing healthcare environment is inspiring and feasible. This also strengthened the NVFK vision and different themes were explored. To contribute to the '2040' aim these themes must be taken into account.

Relevance for users and families:

"In 2040 Dutch children, with and without a chronic disease or disability, are the healthiest children in the world". This vision can only be executed in participation with children with chronic diseases and disability, and their interprofessional health care providers to learn from and stimulate eachother.

Exploration of Service Providers' knowledge and application of the 'F-Words for Child Development' in Children's Disability Services in Ireland

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Introduction: The 'F-words for child development' is a new framework for service delivery, which was adapted by Rosenbaum and Gorter (2012) from the ICF framework (WHO, 2001). Together these 'F-words' (Function, Family, Fitness, Fun, Friends, and Future) present a holistic, strengths-based approach to child development that highlights the core areas essential for optimal child development. This framework is in the early stages of implementation in Ireland, and little is known about service providers' perspectives. This study aims to explore service providers' knowledge and attitudes towards the 'F-words for child development', and their need for further training in this area.

Methods: A mixed Methods research design has been employed. Ethical approval has been obtained from the Health Service Executive, Ireland. Data is being collected through an online survey. This includes the standardized Measure of Processes of Care for Service Providers (Woodside et al. 2001) and a previously used Likert scale (Soper et al., 2020) based on the Theory of Planned Behavior. Services providers in all 91 Children's Disability Network Teams in Ireland are being invited to take part in the study.

Results: Service providers' knowledge, attitudes, application and behaviours towards the 'F-words' will be reflected. Service providers' self-identified needs for training will also be presented.

Conclusion: Children's Disability Services in Ireland are being re-configured, with service providers' roles undergoing significant change. Findings will provide critical information on service providers' perspectives of the 'F-Words' framework within children's services, and the need for further training in this area.

Relevance for users and families:

Child and family centered practice should be central to all Children's Disability Service Teams. The 'F-Words for Child Development' may provide a framework for service providers and families to develop therapy goals in a holistic, family-centered way. Obtaining service providers' knowledge, attitudes and need for further training in the 'F-Words' will provide critical information on how to move forward in this area.

Communication Function Classification System: Cultural adaptation, validity and reliability of the Greek version for children with cerebral palsy

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Introduction: The Communication Function Classification System (CFCS) classifies people with Cerebral Palsy (CP) according to their communication performance. However, the Greek version of CFCS has not been developed yet, while there is currently no evidence for its psychometric properties. The purpose of this study was the cultural adaptation of CFCS in Greek and the investigation of its validity and reliability in children with CP.

Material and Methods: The English version of CFCS was translated into Greek and cross-culturally modified by a panel of experts. A back translation of the Greek version of CFCS was confirmed by the CFCS team. Inter-rater reliability between Speech and Language Therapists (SLTs) and between SLT and parent was evaluated using intra-class correlation coefficient (ICC). Validity was investigated by associating the Greek version of CFCS with the Greek version of Eating and Drinking Ability Classification System (EDACS) and Gross Motor Function Classification System (GMFCS), using ordinal logistic regression. Parents of children with CP aged 2 to 18 years and SLTs with minimum 5 years of experience were recruited.

Results: One hundred twenty one children with CP, GMFCS levels I-V, and eight SLTs organized in pairs were included. Inter-rater reliability was excellent (ICC=0.943) between SLTs and good (ICC=0.768) between SLT and parent. Both EDACS and GMFCS were significant positive predictors for the Greek version of CFCS.

Conclusion: The Greek version of CFCS is a valid and reliable classification system. It can be used to classify communication performance in Greek children with CP.

Relevance for users and families:

These findings suggest that the Greek version of CFCS has adequate inter-rater reliability and validity to meet quality standards. This study advances our insights in the classification of communication performance of children with CP in Greece. We recommend that parents/caregivers, SLTs and researchers can use the Greek version of CFCS in clinical and research practice.

Impacts of family-centred service education on health professionals working in paediatric disability: a scoping review.

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Introduction: Family-centred service is an approach to practice characterised by collaborative relationships and a focus on family strengths. It is widely accepted as best-practice in childhood disability however implementation is variable. This scoping review aimed to explore the impact of education targeting family-centred service and the strengths-based framework of the International Classification of Functioning, Disability & Health (ICF) for health professionals working with children with disabilities and their families.

Methods: The review followed JBI Methodology for scoping reviews. Seven databases were searched, and Results imported into Covidence Systematic Review software for deduplication, screening, and data extraction. We reviewed program content, development and delivery, and the impact on knowledge, attitudes, behaviours, and self-efficacy, of health professionals.

Results: Of 13,434 references retrieved, 24 were included that evaluated educational outcomes. Preliminary Results indicate that the content of education varied between processes of family-centred service, and contextual factors important to working with children with disabilities and their families. There were few studies targeting the ICF than family-centred service. Delivery Methods typically aligned with principles of adult learning. Some programs were developed or delivered collaboratively by parents and professionals. Programs had a positive impact on health professional perspectives and confidence of delivering family-centred services; however, support in addition to education was required to change practice and sustain these changes.

Conclusion: Education programs typically improved health professional perspectives and confidence in family-centred approaches. Outcomes were enhanced with parent involvement in the program, but impact on behaviour was variable.

Relevance for users and families:

Understanding how and what health professionals learn about family-centred approaches to practice, and the impact of education, will support program development to promote adoption of strengths-based, family-centred behaviours. The aim is to encourage collaboration and partnership in practice, to prioritise child and family goals and provide support that builds on the strengths and resources of the child, family and community.

“I’d probably trip over it because it’s bumpy” Exploring lived experiences of a child with cerebral palsy in everyday challenging environments

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Introduction: This abstract presents a case-study from ‘The Walk-Along Project’, a qualitative investigation using walk-along interviews to explore lived experiences of children with cerebral palsy (cwCP). The Walk Along Project aims to investigate challenging walking environments (e.g. uneven surfaces) that increase fall-risk more than level walking(Malone et al., 2015). Walk-along interviews can generate rich insights by discussing experiences while walking(Ergler et al., 2021).

Patients and Methods: One 13-year-old child with cerebral palsy (GMFCS I) and their parent participated in a walk-along interview lasting 30 minutes. Chest mounted cameras (Kaiser Baas X450) and clip-on microphones (RODE GO II) captured walking environments and conversations during the interview. Interpretive description(Thorne, 2016) was carried out in NVivo to identify key themes.

Results: Several environments were identified by the child and parent during the interview as challenging (likely to cause a trip or fall), these were described as “bumpy” surfaces (e.g. cobbles), “raised” obstacles (e.g. kerbs), “slippery” surfaces (e.g. gravel) and non-“bumpy” paths (e.g. uphill). The least challenging environments during the interview were described as “flat” surfaces. Several interacting factors made walking in these environments more challenging (reduced concentration, vision, footwear, tiredness) whereas several factors controlled by the child (“cautious” walking, avoidance, awareness of hazards) reduced the likelihood of falling.

Conclusions: This case-study provides initial insight beyond what is currently known about the types of environments (e.g. “bumpy” surfaces), that increase fall-risk for cwCP. The Walk-Along Project is ongoing with a larger group of cwCP to explore how challenging environments and interacting factors influence falls.

Relevance for users and families:

Understanding real-world causes of falls by listening to perspectives of children and parents is vital, since typical walking analyses is carried out over level-ground and therefore overlooks everyday challenges to balance(Malone et al., 2015). This case-study provides initial insight into the potential multi-faceted causes for falls (e.g. vision, concentration), that are not considered in typical analyses and provides scope for future work informing fall prevention.

A systematic review of interventions promoting physical, psychological and socioeconomic well-being of parents of children with neurodevelopmental disabilities

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Objective: To summarize evidence on the effectiveness of interventions addressing physical, psychological or socioeconomic well-being of parents of children with neurodevelopmental disabilities (NDD) (0-18 years).

Methods: We searched four databases (CINAHL, Embase, Medline and PsycINFO) to identify randomized controlled trials (published 2000-Jan 2022) that explored intervention effectiveness specifically aiming to improve parental well-being. Two authors independently performed title/abstract screening, full-text screening, data extraction and risk of bias using A Revised Cochrane Risk-of-Bias tool (RoB 2). Meta-analysis was conducted using RevMan. The quality of evidence was assessed using The Grading of Recommendations, Assessment, Development and Evaluation.

Results: Overall, 44 randomized control trials met the inclusion criteria (n=2,569), 25 of which were included in meta-analysis. Most Results explored the effects of programs on psychological well-being and were assessed to be of low to very low-quality evidence. Depression was improved by two types of programs: psychosocial and Acceptance and Commitment. Psychosocial programs did not demonstrate effectiveness for mental health, caregiver burden and quality of life. Resiliency programs improved stress and social support, while inconclusive Results were observed for mental health and resilience. Spiritual programs did not improve the quality of life.

Conclusions: There is predominantly low-quality evidence that could support practice implementation. The effectiveness of programs is yet to be confirmed in well-designed, high-quality studies. However, the effects observed in this review suggest that (semi)structured support programs for parents of children with NDD, specifically targeting parents' needs, have the potential to advance their health and well-being.

Relevance for users and families:

Parents of children with NDD are under a great risk of poor health and well-being outcomes that are believed to be associated with their intensive parenting role. In this study, we synthesized the literature on structured and semi-structured programs that could address their needs and affect their health and well-being. Our Results can assist organizations, policy makers and parent advocates in determining service implementation priorities and action plans when addressing parents' needs in their setting.

Understanding the role of Emotional Intelligence of mothers in the rate of increase in the Developmental Age of children with NDD

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Introduction: As parents are the primary caregivers of their children, parental characteristics contribute majorly towards their ward's holistic development. The present study aimed at assessing the role of emotional intelligence of mothers in the rate of increase in the developmental age of children with NDD.

Patients and Methods: A longitudinal, ex-post facto research was conducted with 20 children and their mothers. The children were below the age of 10 years and diagnosed with mild, moderate, severe, or profound degree of ASD, ADHD, and/or GDD. Data on emotional quotient (i.e., EQ) of mothers, and the developmental ages (DA) of the children were assessed using SSEIT, and Griffiths III and BSID-III, respectively. The rate of increase in the DA was measured as the decreasing difference between a child's DA and his/her chronological age (CA) before and after adhering to the treatment plan for a duration of 8 months. The obtained data were analyzed using descriptive and inferential statistics.

Results: The findings indicated that mothers' EQ was positively correlated to the rate of improvement in the DA of children with special needs. This suggests that the higher the mothers' EQ scores on the full-scale measure of SSEIT as well as on each of its domains, the lesser the difference between children's DAs and CAs.

Conclusion: There exists a positive relationship between the mother's emotional intelligence and the rate of improvement of a child with special needs in terms of his/her developmental age.

Relevance for users and families:

By measuring the effect of mother's emotional intelligence on the rate of increase in the developmental age of the child with special needs, we understand that it is an effective tool to predict the prognosis and later, to effectively frame the course of the treatment.

Facilitations: a modality of care for children with visual impairment

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Introduction: The Robert Hollman Foundation, which offers support to the development of children with visual impairment and of their families, designed a modality of care, called "Facilitations" to respond to the necessity of the families to have a practical, user-friendly, efficient tool to remind them all the oral suggestions listened during the consultancies. Facilitations are specifically designed drawings on a simple sheet, with appropriate captions, which can be also modified by the professionals in order to be adapted and customized to every single child.

Methods: A questionnaire regarding Facilitations was created to be sent to the families, asking their opinion regarding their satisfaction, the clearness, the adequacy, the usability and the usefulness of the Facilitations. In the period January-June 2022, 48 questionnaires were sent, of which 21 were filled and returned to the Foundation.

Results: parents reported 100 % of satisfaction, of which 71,4% with the maximum score. Parents also wrote that facilitations are clear (95,2%), adequate (95,3%), user-friendly (76,2%), helpful for their children (61,9 %), shared with other people belonging to the children daily context (85,7%).

Conclusion: Facilitations is not only a tool but also an efficient modality of care because it helps parents to keep in mind what is essential for their children development in the daily life, being relevant both for families and professionals.

Relevance for users and families:

"Facilitations" is a co-shared modality of care helping the parents to keep in mind and to apply what is essential for their children development in the daily life, as well as it offers the opportunity to be shared with professionals and people living in the child's daily environment.

Examination Of Quality Of Life And Depression Level Of Mothers with Disabled Children During the Covid-19 Pandemic Process

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Introduction: As a result of the coronavirus, COVID-19 pandemic, the measures taken and the losses experienced in our country, as well as all over the world, have caused people to come under stress. The aim of our study is to examine the quality of life and depression level of mothers with disabled children during the COVID-19 pandemic.

Materials and Methods: Our study included 56 children (26 women, 30 men)with disabilities between the ages of 2-15 (7.16±3.86 years, BMI: 18.69±7.38) and those between the ages of 22-53 (37.26 ±7.43 years, BMI: 27.25±5.25), 56 mothers were included. Demographic data of the participants were recorded. The quality of life of the mothers was evaluated by Nottingham Health Profile (NHP) and the depression level was evaluated by Beck Depression Inventory (BDI).

Results: The average total NHP score of mothers with disabled children was found to be 133.09±104.04 and the average BDI score was found to be 10.80±7.79. There was no statistically significant difference between the quality of life of the mother and the level of depression between the groups according to the mental or physical disability of the children ($p>0.05$).

Conclusion: The result of our study shows that the quality of life of mothers with disabled children is low and their psychological status is affected during the COVID-19 pandemic. It was thought that this condition may be due to the disability of their children and the stress brought on by the pandemic.

Keywords: COVID-19, Disabled Children, Mother, Quality of Life, Depression

Relevance for users and families:

As a result of the coronavirus COVID-19 pandemic, the measures taken and the losses in our country, as in the whole world, have caused people to be stressed and have psychological problems. The thought that the children of mothers with disabled children will be more affected by this situation due to their health problems, as we mentioned in our study, caused mothers to become depressed and their quality of life to decrease.

Early assessment and goal-directed treatment in children with a high risk of CP

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Background: Goal setting is central to the rehabilitation process and has been described as core skill of the rehabilitation professional. It supports gaining a consensus with respect to shared planning and direction of intervention, which is meaningful to children and families.

Our aim was to Identify the effectiveness of goal-directed treatment in children with a high risk of cerebral palsy. Also, to understand how the early assessment and concept of goal setting link with GAS and the ICF frame.

Methods: Forty-three children with a high risk of cerebral palsy were evaluated with HINE (Hammersmith Infant Neurological examination) and MRI, to support goal setting.

Including criteria were children's age, low scores in HINE – less than cut-off scores, PVL on MRI. The range of the children's age was from 3 to 12 months. HINE scores vary between 19 to 57. Reassessment with HINE was performed every three months during 12 months of follow-up.

The quality of the goals was assessed with defined SMART criteria, while goals were defined by the 5Q format and GAS.

Results: Forty-three children were assessed, only thirty-four were eligible for this study. In Twenty-nine children after 12 months of follow-up and treatment, HINE scores were increased to 5-15 points (range from 30-69). In five children HINE scores were unchanged.

Conclusion: Our study showed, that early assessment and early intervention with goal-directed treatment leads to improvement of outcomes in children with high risk of CP. HINE scores significantly increased in most children during 12 months follow-up.

Relevance for users and families:

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Perceived barriers and facilitators to adhere to physical therapy appointments for caregivers of children with neuromotor disabilities

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Introduction: Primary caregivers (PCs) of children with neuromotor disabilities (NMDs) in Suriname, a middle-income country, show low adherence rate to physical therapy (PT) appointments according to the Suriname Cerebral Palsy register and PT appointment data. This study aimed to identify the barriers and facilitators for PCs of children with NMDs to adhere to PT appointments in Suriname.

Methods: A qualitative study design was used. Data was collected from ten participants via in-depth interviews. The Socio-Ecological Model was used as a conceptual framework to analyze and categorize the data.

Results: Major barriers that emerged from the interviews were difficulties with transportation, financial challenges for transport and PT treatment, lack of knowledge of disability and PT services, perceived factors related to health care service (HCS) and lack of financial support from the government. Major facilitators were related to having a means of transportation, receiving support from family members and satisfaction with PT treatments. Policy measures of insurance companies were perceived as both barriers and facilitators.

Conclusion: PCs encounter numerous barriers and few facilitators on all socio-ecological levels to adhere to their child's PT appointment. It is notable that majority of PCs were unemployed and had lower educational achievements. Other remarkable Results are perceived factors related to HCS such as limited referral rate and emphasis of physicians to PT services, difficulties receiving financial aid and policy of insurance companies.

Relevance for users and families:

This information can guide physical therapists and other health care providers to increase adherence of PT treatment for children with NMDs. More importantly, governmental institutions, insurance companies and other policy makers should be aware of the barriers and facilitators PCs encounter as they are more influential in creating policies and strategies to facilitate adherence.

Examining potential of an online coaching programme to support parents of disabled children to meet meaningful family goals

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Introduction: Occupational performance coaching (OPC) for parents of disabled children is a strengths-based self-management approach. Emerging evidence supports potential for remote/telehealth delivery of OPC. This paper reports on OPC provided via telehealth to UK-based parents.

Patients and Methods: Eight families of disabled children engaged in four to nine online coaching sessions with occupational therapists who had received introductory training and mentoring in OPC. The Canadian Occupational Performance Measure (COPM) was used to set meaningful goals and evaluate parent perception of occupational performance and satisfaction. The Parenting Stress Index 4th edition Short Form (PSI-4-SF) was completed pre- and post- intervention. Expert- and self—rating of sessions used the OPC fidelity measure (OPC-FM). Data were analysed descriptively.

Results: Parent-set goals related to school, self-care, leisure and family relationships. COPM performance ratings improved (mean difference -3.29; CI: -4.9 to -1.79); 6/8 parents reporting meaningful change (≥2 points). COPM satisfaction ratings also improved (mean difference -3.99; CI:-5.9 to -2.1); 7/8 parents reporting meaningful change. Average stress decreased by 10 points with greatest decreases noted in parental distress subscale. Fidelity was low: average of 33% for initial sessions and 61% for subsequent sessions.

Conclusion: The online coaching programme showed potential to support UK parents to meet meaningful goals and address parent stress. Results should be interpreted with caution due to small sample, lack of control and missing data. Fidelity to intervention was low and it is recommended that therapists seek further OPC training. Replication of research with larger sample and closer monitoring of fidelity is recommended.

Relevance for users and families:

This paper shows that occupational performance coaching was associated with improved outcomes for families of disabled children and that parent-mediated interventions may offer benefits for families as well as individual children. Online interventions are relevant to explore as they may be lower cost and more convenient for families of disabled children than face to face sessions. Fidelity scores highlight the comprehensive training and development needs for therapists to provide occupational performance coaching to families.

To evaluate the parenting stress among fathers and mothers of special need children.

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Introduction:- Studies have shown that parents of special needs children have stress. Specially mothers have more stress than fathers. In most of the cases mothers stress are being ignored and in many cases mothers are not aware of their own stress. most of the time they cannot share their stress. This leads to many emotional problems. Although there are not many researches found. Therefore, the aim of this study is to evaluate the parenting stress among fathers and mothers of special needs children.

Patients and Method: The sample is 30 parents of special needs children. They were selected from Nabajatak Child Development Centre. Quantitative Method was used to collect data where questionnaires were distributed among samples. Tool that was distributed among them was: parenting stress index(PSI)

Results: The Results showed differences between fathers and mothers in the 3PSI sub scales includes PSI child domain score, PSI parent domain score and the total stress index. Mothers had significantly more stress than fathers.

Conclusion: These findings showed that mothers of special need children have more stress than fathers. Therefore while dealing with special needs children we need to keep in mind about mothers stress.

Keywords: Parenting Stress.

Relevance for users and families:

parents becomes stressed as they could not take their child in a social gathering because of their behavioural issues. relatives blames the parents because of the condition of their child.

Developmental disorders over time: changes and challenges

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Introduction: Neurodevelopmental disorders constitute a diagnostic challenge, especially in the first years of the child. The challenges for this are twofold: first dealing the child's difficulties at all levels of development, and second the emotional impact of the diagnosis for the families/caregivers, which often generates family stress and affects the bond with the child. The latter having negative repercussions on the child's own development.

Patients and Methods: In this study we analyze the changes in diagnostic orientation on a sample of 178 children treated in our Disability Outpatient Health Centre for neuropsychological assessment and therapies using a global, interdisciplinar approach, who had previously been diagnosed and treated in our Early Development Center (0-6 years), within Spanish public health services.

Early Results: So far it has been observed that in the 37% of cases there has been a relevant change in the diagnostic orientation in the transfer from the Early Development Center to the Disability Outpatient Health Centre, with a mean age of definitive diagnosis of 8 years, 3 months, and with a significant incidence of comorbidities with other neurodevelopmental disorders. In most cases, a change in diagnosis changed the therapeutic, familiar and educative approach.

Conclusions: Diagnosis in neurodevelopmental disorders should be a shared and continuous process over time integrated with therapies and with child's environment, involving professionals, families, health, education and community services, which requires to health practitioners listening, communication and empathy skills beyond technical abilities.

Relevance for users and families:

There are few studies on the evolution of neurodevelopmental disorders over time. Diagnostic orientation in an evolutionary perspective is a crucial process, as it determines the therapeutic approach and has a high emotional impact on the family/caregivers, as well as consequences on the adaptations of the child's environment.

Preliminary Results of a Scoping Review of Technologies Evaluating Cognitive Function in Children with Cerebral Palsy

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Introduction: Cognitive impairment is increasingly recognized as a commonly accompanied disturbance in children with cerebral palsy (CP). Considering cognitive function is a complex and multicomponent term, there is a need for feasible Methods to assess cognition. Automated **Methods** in diagnostics are promising for the assessment of cognitive function in people with different neurological disabilities, as they can be used in various settings and environments. This brief review explores the technologies used to evaluate cognitive function in children with CP.

Patients and Methods: A scoping review was conducted based on the peer-reviewed articles in MEDLINE and ResearchGate databases in January 2022. The inclusion criteria were experimental studies published from 2012 to 2022 involved participants and included technologies developed to evaluate cognitive function. Authors of the study, publication date, population, study features, details of the cognitive assessment tool, secondary outcome measures, and psychometric properties were extracted.

Results: We obtained a total of 666 articles. After screening, 39 articles with 579 participants were included in this analysis. Most technologies focused on motor learning and navigation skills, including spatial performance and visuospatial integration. Considering the technological approach, there were two main types: dual-tasking technologies that assess and train both motor and cognitive functions using virtual reality, augmented reality, or exoskeleton, and automated solutions that can be coupled with other sensors.

Conclusions: There are different technologies aimed at assessing cognitive function in children with CP. The methodological quality of the screened studies should be performed to conclude on clinical applicability of technology-based diagnostic tools.

Relevance for users and families:

We briefly reviewed existing technologies assessing cognition in children with cerebral palsy. Automated diagnostics is an innovative approach allowing assessment in different settings, including homes. More reviewed tools are affordable and can be used in countries with diverse economic incomes.

Introduction - the importance of early diagnosis and intervention.

Dina Sheffer Perez[1]

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Introduction - the importance of early diagnosis and intervention. Tom was born on time, with a brain Injury due to a prolonged and complicated birth. The diagnosis- cerebral palsy LF HEMIPLEGIA due to 2 SARANT -HIE Independent clinic, Dina Sheffer Neuro-developmental Physiotherapy, Kadima, Israel

Method: At the age of 5 months, the parents began an intensive, integrative, physiotherapy treatment with a high frequency. Periodic home visits were conducted with maximum adaptation of the natural environment to Tom's needs. Videos of the exercises were taken. The target was a goal-oriented and precise work utilizing the brain plasticity to overcome the damage. The method of operation was teamwork. The parents and the extended family functioned as a small child development center

The parental response, attentiveness and compliance was maximal (during the COV-VID crisis and curfew), taking responsibility and understanding that this is a critical period ,window of opportunity of time for the rehabilitation of Tom's brain and body.

Results: Tom began to respond very quickly to the intense and precise work. His left hand, which was closed and fisted become a functioning hand. He began to crawl, sit, stand, and finally at the age of one year and two months he achieved independent walking.

Today Tom is a healthy, 4-year-old boy.

Conclusions:

- Early detection, intervention, and immediate referral for professional help.
- Maximum responsiveness of the nuclear and extended family.
- Precise and intensive work in the very early stages - with specialized professional

Relevance for users and families:

- Early detection, intervention, and immediate referral for professional help
- Maximum responsiveness of the nuclear and extended family.
- Precise and intensive work in the very early stages - with specialized professional

Analysis of 4 years of pediatric sialorrhea management by botulinum toxin application: anatomic-landmarks vs ultrasound guidance.

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Introduction:The management of saliva loss in children with multiple disabilities is of extreme importance. The intraglandular application of botulinum toxin A has evidence of efficacy. In the pediatric rehabilitation, its use is limited by the need for patient's immobility during the procedure.

Patients and Methods:We report the experience of 4 years of intraglandular application of botulinum toxin A, in an outpatient Pediatric Rehabilitation setting. From a total of 29 patients, with neurological conditions, 16 were eligible for study. Seven female and 9 male, mean age 10,3 years and mean pre-procedure salivation loss of severity 4 and frequency 3,6. 23 procedures were performed: 15 under ultrasound (US) guidance with patient sevoflurane sedation, and 8 by anatomic landmarks (non-US) with no sedation. In the US group, at 1 and 3 months post procedure, we found a statistically significant difference in drooling severity and frequency.The improvement peak was seen in the third month after infiltration ($p < .001$).It was not found a statistically significant difference in pre vs post procedure on the non-US group. The comparison of the two groups supported the use of US, with evidence at one and three months ($p < .001$), and at six months post procedure ($p < .048$).We could not correlate the contribution of sedation to better Results, only infer an indirect correlation.

Conclusion:The Results are in line with the international trend and guidelines on the use of US in this procedure. The relevance of sedation and total immobility of the patient should be further accessed.

Relevance for users and families:

The authors highlight the importance of US guidance on botulinum toxin infiltration of the salivary glands and also the need for multidisciplinar planning with anesthesiology.

TranXition Program: "I suddenly have a young adult in the house. How did that happen?"

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Introduction: Transition to adulthood represents a complex process for youth with physical disabilities, often experienced as "hanging over a cliff". Best practices in transitional care recommend that the youth be at the centre of the interventions. This involves youth-driven goals, experiential interventions in real-life contexts and an interdisciplinary, flexible offer of service, designed in partnership with the users.

The TranXition team of the Lethbridge-Layton-Mackay Rehabilitation Centre has embraced this paradigm by developing an innovative program addressing four spheres of opportunities: physical and mental well-being; residential autonomy; socialization; work and studies.

Patients and Methods: TranXition offers a large spectrum of real-life-context group interventions for youth and emerging adults between 15-25 years-old with diverse motor, visual, hearing and language disabilities. Parents are also supported through various interventions.

An initial, holistic assessment allows to orient the youth towards the optimal intervention, based on their profiles, needs and priorities. This includes the Canadian-Occupational-Performance-Measure, pre-post outcome measures selected to evaluate specific group objectives, and semi-structured interviews. This process, done in partnership with the youth, leads to a continuum of services aligned with their progress and evolving needs.

Results: Results show that the TranXition approach, focusing on youth-driven goals and exposure to real-life challenges, contributes to the youth's well-being and participation. Specifically, it increases self-awareness, self-esteem, independence and social interactions. As such, it plants the seeds for greater empowerment and self-determination; necessary to foster meaningful participation.

Conclusion: Partnership with youth as full participants, combined with an experiential, flexible, interdisciplinary approach is key to support successful transition.

Relevance for users and families:

Youth with physical disabilities and their families transitioning to adulthood often feel unsupported due to the lack of resources to navigate this complex period. The TranXition program aims to bridge these gaps and support youth and families in gaining the necessary life-skills to transition and strive in adulthood. Partnership with youth, parents and other community partners is at the core of the intervention model, which proves to be an impactful way to provide rehabilitation services.

A mixed-Methods systematic review of health literacy in adolescents and young adults with cerebral palsy, and the relationship to quality of life

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Introduction: While adolescents and young adults with cerebral palsy have high rates of health service utilisation and support, little is known about their access to, and integration of health-related knowledge. This systematic review aimed to identify evidence about health literacy development in young people with CP, establish current practices used to access and build health knowledge, and explore associations between health literacy and quality of life (QoL).

Methods: Five databases were systematically searched. Mixed Methods data were synthesised using a convergent integrated analysis framework. The JBI critical appraisal tool and Mixed **Methods** Appraisal Tool were used for assessing quality.

Results: Ten articles with n=288 participants were included. There was no common definition of health literacy, as it applies to young people with lifelong developmental disability. Capacity building, development of identity and self-management skills were identified as evidence of health literacy in young people with CP. Elements that assisted young adults to access information and build their health literacy were: identifying specific information needs; modes of information access; the opportunity to learn through family, peers and mentors; learning experientially through participation and self-reflection; and the role of healthcare providers as a major source of health information. Three studies loosely explored the relationship between health literacy and QoL.

Conclusions: Young people with CP have a crucial need to obtain, process and utilise health information, to make informed health-related decisions about their lives. Building capacity in early adulthood through accessing the appropriate support and services will assist their participation in healthcare decision making.

Relevance for users and families:

Young people with CP identify their families, peers, and healthcare providers as being critical to their development of health literacy. Working with young people with CP to support them in identifying their health literacy needs, accessing relevant information, and encouraging them in experiential learning is key to the development of meaningful participation in healthcare decision making, during this important transitional life stage.

Understanding play, well-being and participation: A complexity framework

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Introduction: Play is widely considered as vital to the health and well-being of children and a typical form of participation. Yet, for children with disability and special needs, play is frequently treated as a therapeutic agent, rather than a goal in its own right. Furthermore, these children often face barriers in play participation, a complex phenomena. To understand the role of play in the lives of these children, we need to understand the factors that affect children's play. Complexity theory, an approach to understand complex systems, their factors and relationships, can be of use here. The purpose of this study was to review the recent literature to identify a complexity framework to inform the understanding of play in order to support children's well-being and participation.

Patients and Methods: A multifaceted approach to the literature was undertaken to create a complexity framework for understanding children and play, including children with disability and special needs. This presentation will focus the latter group.

Results: A preliminary complexity framework with multiple elements and sub-elements was identified to support our understanding of children's play and how to enable it. The findings indicate that play continues to be considered a tool rather than as a participation goal.

Conclusion and relevance for users and families: A complexity framework can be useful in broadening our perspective on play. It is important that play be a goal it its own right to ensure better futures for children with disability and their families.

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Participation in physical activity for people with different disabilities: feasibility and effects of physical activity on prescription (PAP)

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Introduction: People with disabilities experience challenges to reach WHO's recommendations for physical activity. Physical activity on prescription (PAP) is a well-established method to enhance physical activity in adults. The Swedish PAP has been chosen as best practice by the European Commission and the WHO. In children with cerebral palsy aged 7-11 years, PAP has shown to be feasible to increase participation in physical activity. It is important to study PAP when applied on a broader group of patients than previously studied. The aim is to study feasibility and effects of PAP in physically inactive persons with autism, intellectual and physical disabilities.

Patients and Methods: In total 80 children and adults will participate in PAP; 20 children aged 8-17 years in each group with autism, intellectual and physical disability, and 20 adults with disabilities. PAP consists of a written agreement between each participant and the physiotherapist based on Motivational Interviewing, Canadian Occupational Performance Measure and Goal Attainment Scaling. Data about individual goals, physical activity and quality of life will be collected at 3 months prior to the intervention, just before the intervention starts, and at 3, 6, 12 and 24 months after the intervention. Data on cost- effectiveness and feasibility will also be collected.

Results and Conclusion: The findings are expected to show feasibility, effects and cost-effectiveness of PAP on participation in physical activity for people with different disabilities across the life span.

Relevance for users and families:

Participation in physical activity is crucial for physical and mental health throughout lifetime.

Awareness-raising and prevention of abuse in elderly people with cerebral palsy

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Introduction: Abuse is any isolated or repetitive act, or lack of appropriate action, occurring in any relationship of trust, which causes harm or discomfort to the person. The aim of the study is to analyse the sensitivity and the tools available to organisations to identify, define, detect and prevent different situations of abuse in the care of people with cerebral palsy.

Methodology: Cross-sectional descriptive study. An ad hoc questionnaire was drawn up following the structure of the European Association of Services Provides for People with Disabilities. The Federation contacts the nine entities in the Community to collect data on their position on abuse.

Results: The training received by the Federation allows for a public definition and protocol, with written standards in 55.5% of cases. They ask for references when hiring a worker, following the law. And although there is a prevention officer, a commission, protocols for challenging behaviour and concern for the defence of rights, the entities do not have specific indicators of abuse, nor external commissions to facilitate their work.

Conclusion: These data serve to initiate consensual actions for prevention and protection against abuse. The ability to detect when a person is being abused stands out. First consider the possibility that a user may be a victim and be attentive to changes and verbalisations by recording the information. Strategies to be implemented are to design a specific action plan, to involve professionals without worrying about the image of the entity and to accompany the victim with cerebral palsy.

Relevance for users and families:

It is advisable to carry out this analysis with different members involved (people with cerebral palsy, families, professionals), in order to effectively assess the position in the face of abuse and to detect and intervene effectively in the face of the violation of the rights of these people. Identifying suspicions, indications or evidence can be useful to detect cases and guide all the agents involved in the judicial process to be followed.

An initial evaluation of co-occurrences of mental health problems among transition-aged youth with physical disabilities

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Introduction: Wellbeing of youth with disabilities may be hindered by decreased participation and difficult transitions into adulthood. To advance knowledge on mental health problems and physical disability's co-occurrences, this study describes the frequency of mental health problems, measured by the Behavior Assessment System of Children (BASC-3), among transition-aged youth (14-25 years, median=20) with physical disabilities and examines the association between mental health problems and sex, age, and number of functional issues.

Patients and Methods: Participants (n=33) completed a demographic questionnaire and the BASC-3. Frequency of BASC-3 scales falling within 3 categories: 'norms', 'at risk', and 'clinically significant' were reported. Crosstabs and Chi-square tests were used to examine the association between BASC-3 scales and sex, age (< and ≥ 20), and number of functional issues (< and ≥ 6).

Results: Overall, the most common subscales 'at risk' were 'somatization', 'self-esteem', 'depression' and 'sense of inadequacy'. Participants with a higher number of functional issues (≥6) were more likely to fall within 'at risk' or 'clinically significant' categories across 20 (out of 22) BASC-3 scales, and female-youth tended to fall more within 'at risk' or 'clinically significant' categories for 8 scales. Younger participants (<20) were in the 'at risk' or 'clinically significant' categories for 7 scales.

Conclusions: These preliminary findings support the co-occurrences of mental health problems emerging in youth with physical disabilities, the applicability of BASC-3 as a measure capturing mental health problems and highlight initial trends especially across functional levels. Further studies on the factors affecting these co-occurrences are warranted.

Relevance for users and families:

Findings could increase awareness of both youth and clinicians on the co-occurrences of mental health problems during this complex transitioning phase faced by youth with physical disabilities. This in turn can facilitate goal setting focused on improved emotional functions. Results can also support the use of the BASC-3 as a measure that can capture mental health problems among this population especially for those with greater number of functional issues.

Clinical Utility of the Collaborative Process for Action Plans to Achieve Children's Participation Goals

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Introduction: Although the importance of family-therapist collaboration for establishing participation goals is recognized, scarce attention has been paid to how the action plan to achieve the goal is collaboratively developed. The Collaborative Process for Action Plans to Achieve Children's Participation Goals includes questions to identify a child's abilities, family and environment considerations, development of intermediate objectives (what needs to happen to achieve the participation goal), and then integrating information to develop the action plan and the person(s) responsible for each action. The process fosters sharing of information and co-creating interventions to build on strengths and enhance capacity.

Participants and Methods: Ten professionals with 14–33 years of experience in pediatric rehabilitation gave written comments on the content, usefulness, feasibility, and clarity of the Finnish translation. Ten family/therapist teams piloted the tool in practice after which they completed questionnaires that included open-ended questions on content and usefulness of the tool. Responses were analyzed through inductive content analysis.

Results: Minor edits were made to the wording of the Finnish version. From parents' and professionals' perspectives, the tool promotes engagement, considering the goal from many viewpoints, and joint development and commitment to the action plan. The limitations include that the collaborative development of an action plan is time-consuming, the tool contains some unfamiliar words, and the process requires preparation.

Conclusion: The Results were used to develop a manual with case examples and instructions to support the utilization of the tool. Familiarity with collaborative, solution-focused approaches, and participation-based interventions are considerations for use in practice.

Relevance for users and families:

The tool guides families and professionals to collaboratively assess the child's interests and abilities, the family's situation, factors in the environment, and to identify solutions and outcomes to achieve children's participation in the desired activity. The manual and form for the Collaborative Process for Action Plans are freely available online in Finnish and English. The process can be adapted for child's everyday life and pediatric rehabilitation contexts.

Parental stress and visual perception are associated with participation children with mild cerebral palsy

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Introduction: Cerebral palsy (CP) is often accompanied by communication, cognitive and psychological difficulties that may impact participation at home, school and community. This study aims to explore in depth the role that relevant demographic, clinical, neuropsychological and psychosocial variables play in the participation of children with mild CP.

Patients and Methods: Fifty-four children (mean age 10 years and 2 months, SD 1 year 7 and months, 28 females) were included in this cross-sectional study. Participation was assessed by proxy-reported Participation and Environment Measure for Children and Youth (PEM-CY) questionnaire. Relationships between participation scores and demographic (e.g. socioeconomic status, among others), clinical (e.g., motor status), neuropsychological (e.g., visual perception) and psychosocial (e.g., parental stress) variables were explored using bivariate correlations and p-values were corrected for multiple comparisons (Holm-Bonferroni correction). Those variables that correlated significantly were introduced in multiple linear regression models.

Results: Parental stress (p=0.003, 95%CI=-0.07/-0.2, β=-0.38, t=-3.13) and visuoperception (p=0.004, 95%CI=0.07/0.34, β=0.37, t=3.05) were significant explanatory variables for home participation (R2=0.387). No demographic, clinical, neuropsychological or psychosocial variables were significantly associated with community and school participation in our regression models.

Conclusion: Parental stress and visuoperception are importantly associated with home participation in children with CP. These findings suggest that both resources targeting parental stress and visual perception in children with CP may positively enhance their participation. The fact that participation was proxy-reported by caregivers could be influencing no association in other settings different from home, such as school and community participation.

Relevance for users and families:

Caregivers' well-being and cognitive functions in children with CP should be monitored.

Spinopelvic parameters in young children with achondroplasia: ten year follow-up

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Introduction: Thoracolumbar kyphosis (TLK) deformities in children with achondroplasia resolve in 70% of cases one year after independent walking and 90% by 10 years old. Our objective was to evaluate the relationship with spinopelvic parameters, beginning before walking, up to 10 years of age.

Patients and Methods: Patients with achondroplasia with lateral spine radiographs at pre-walking (PW), 1-year post-walking (1YPW), 5 years old (5YO) and 10 years old (10YO) were identified. Development motor delay (DMD), lumbar lordosis (LL), pelvic incidence (PI), pelvic tilt (PT), sacral slope (SS), apical vertebra wedging for height (AVWH), and apical vertebra translation (AVT) were analyzed.

Results: Sixty-two children (32 male, 30 female) were identified. There was no required treatment. Association exists between DMD ($p=0.001$) with TLK > 20°. Twenty-four patients had follow-up at 10YO and were divided into positive PT (7) and negative PT (17). At 1YPW, children with negative PT had higher SS ($p=0.006$), higher LL ($p<0.001$), and lower PI ($p<0.001$). This relationship remained at 10YO follow-up: children with negative PT had higher SS ($p=0.012$), higher LL ($p=0.002$), and lower PI ($p<0.016$). There was no association between PT groups with TLK.

Conclusion: In this largest series to date, spontaneous resolution of TLK in children with achondroplasia was 65% at 1YPW, and 89% in children followed to 10YO. While not predictive of resolution of TLK, the dichotomous presentation of PT in young children with achondroplasia persists at 5 and 10 years of age, and reliably predicts the spinopelvic parameters.

Relevance for users and families:

In children with achondroplasia, thoracolumbar kyphosis reliably self-corrects, and early identification with regular follow-up Helps ensure no treatment is required.

What kind of kyphosis? A novel classification system of thoracolumbar kyphosis in achondroplasia

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Introduction: Spinal stenosis is present in all patients with achondroplasia and is commonly associated with thoracolumbar kyphosis (TLK). Development of symptomatic spinal stenosis can begin in adolescence, becoming more prevalent in adulthood, resulting in pain, weakness, neurogenic claudication, bladder or bowel dysfunction, and, eventually, paralysis. The purpose of this study was to classify deformities of the thoracolumbar junction, determine treatment options, and describe complications.

Patients and Methods: Patients with achondroplasia, TLK, and symptomatic spinal stenosis who underwent operative treatment were selected. Medical records and radiographs were analyzed with minimum of 1 year follow-up. Intra-observer and interobserver reliability were measured.

Results: Forty patients were selected, and the average age was 16±5 years, with a mean follow-up of 5±4 years. We identified four classes: Class 1 involves gradual multi-level TLK with diffuse stenosis; Class 2 involves focal severe TLK associated with apical vertebral wedging and localized stenosis, with a flattened or lordotic thoracic spine above; Class 3 involves severe post-laminectomy kyphosis; and Class 4 involves additional diagnoses related to TLK. Intra-observer index was 0.90 ($p<0.001$) and inter-observer was 0.83 ($p<0.001$). Class 1 patients were treated with posterior spinal decompression and fusion (PSDF), while all others required a combination of PSDF, anterior spinal fusion, and posterior spinal osteotomies. Class 1 patients also had shorter surgical times and lower estimated blood losses.

Conclusion: This novel classification of thoracolumbar kyphosis in Achondroplasia has a high inter-observer reliability and can help guide surgeons treating these challenging patients.

Relevance for users and families:

This study helps identify patients who will require more complex surgical care and reports perioperative risks and radiographic outcomes.

Goal setting practices in paediatric intervention: A systematic review

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Introduction: Involving children in goal-setting for therapy intervention can support motivation and engagement, build self-determination skills and improve goal achievement. However, the best goal-setting approaches and tools for children of different ages or populations are unclear. This study aimed to identify goal-setting approaches reported for children aged 0<18 years with a disability/delay; and examine clinimetric properties of goal-setting tools used within these approaches.

Methods: Six databases were searched (PubMed, EMBASE, CINAHL, Web of Science, Cochrane Reviews, PsycINFO) for papers involving: (i) children 0<18 years with a disability/delay; (ii) a goal-setting approach or tool described in sufficient detail for replication; and (iii) original psychometric data. Data was extracted using PRISMA guidelines and the CanChild Outcome Measures Rating Form. Clinimetric properties were examined using COnsensus-based Standards for the selection of health Measurement INstruments (COSMIN) checklists.

Results: Searches yielded 9590 articles, including 9 eligible goal-setting tools. Considerable heterogeneity was present in approaches, and most were adult-led. Tools were identified for Goal Identification (possible function or performance areas); Documentation (recording baseline performance and/or satisfaction); Readiness (readiness for change level); and Evaluation (outcomes of intervention). Most common tools in research literature were the Goal Attainment Scale and modified Canadian Occupational Performance Measure versions. No tool addresses all goal-setting stages. Clinimetric data focussed on adult-led approaches/tools with limited data for child-led approaches/tools.

Conclusions: Optimal goal-setting should involve a multi-stage, child-centred approach. Current approaches and tools are predominantly adult-led and involve only some goal-setting stages. Child-led goal-setting tools that engage children through all goal-setting stages are needed.

Relevance for users and families:

Optimal child and family-centred care places children at the centre of therapy design and delivery. Allied Health Professionals can use goal-setting approaches and tools recommended in this review to improve their clinical practice with children with disabilities or delays. Researchers can use Results to inform the future development and evaluation of approaches and tools that better support child-led goal-setting in all goal-setting stages. Families can seek practitioners who utilise these best practice approaches and tools.

Performance of the Timed Up and Go with a cognitive dual-task in children aged 5 to 10 years

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Introduction: Walking is complex and requires sufficient balance. In daily life walking-related balance is often accompanied with simultaneous tasks, such as talking. Although a crucial development for both walking-related balance and the ability to DT occurs during 6-7 years, research in this age-group is lacking. Therefore, the aim of this study was to investigate the degree of automatization of walking-related balance during the Timed Up and Go with a cognitive dual-task (TUG+DT) in school-aged children.

Patients and Methods: This cross-sectional study included 26 typically developing children (5-10 years; 15M). The TUG (time) and the cognitive task (enumerated animals) performance in a single and DT condition was recorded. The TUG DT effect (DTEtug) and the cognitive DTE (DTEcog) were calculated, representing the degree of DT interference of either task. A Wilcoxon signed-rank test determined differences between test conditions and between DTEs. A Fisher's exact test explored distribution differences of DT patterns between age-groups. ($p<0.05$).

Results: During the DT, all children showed TUG performance decrements (median: +2.8s;$p<.001$) and 17 children showed better cognitive task performance (median: +1 animal;$p=.006$) compared to single task performance. This led to significant differences between both DTEs (DTEtug-median: -60%; DTEcog-median: 32%;$p<.001$). Age-differences of DT patterns were significant ($p=.038$), of which most 5-7-year-olds (N=7/12) performed poorer on the cognitive task, whereas most 8-10-year-olds performed better on this task (N=12/14) during DT.

Conclusion: Most 5-10-year-old children showed a cognitive-priority trade-off, i.e. sacrificing TUG performance and facilitating the cognitive performance. Hence, walking-related balance is not yet sufficiently automated at this age.

Relevance for users and families:

For 5-10-year-olds, the TUG+DT has little value for clinical use to identify balance automatization deficits in in 5-10-year-old children with potential balance impairments. To detect these deficits in children, the selection of simpler age-appropriate concurrent cognitive-motor tasks must be considered. Future research is needed to explore the most appropriate choice. Children en parents benefit from selecting an appropriate motor-cognitive DT paradigm since understanding and identifying automatization deficits help adapting individualized treatment related to balance deficits.

Converting individual therapy activities into goals can help measure progress in activity and participation

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In therapy, goal setting involves the active participation of clients and family members. The Canadian Occupational Performance Measure (COPM) helps clients and family members to prioritise concerns and rate them based on their performance and satisfaction. If concerns are too broad, therapists help the clients and family members to convert them into a specific activity goal or participation goal. The Goal Attainment Scale (GAS) facilitates further collaboration between the therapist and the client to scale the goal so small steps of progress are recognised. Often goals are set to be achieved at the end of a session or block of therapy. It is difficult to measure what has helped the client to achieve the goal and how the goals are achieved. We are proposing a method to measure the process of how the goals are achieved. In therapy, the client practises a set of tasks with or without help. Individual therapeutic activities or tasks are converted into Specific Measurable Achievable Realistic and Time-bound (SMART) goals. The tasks can be divided into task goals, stability goals, and mobility goals. We are using this method on our clients between October 2022 and March 2023. The Results will show the therapeutic activities that are favourable to the accomplishment of the goal at the end of the therapy session, therapy block and a term. Converting therapy activities into SMART goals can help to track the progress of the clients, study the trends in accomplishing activities and participation, and create evidence for future practice.

Relevance for users and families:

Converting therapy activities into SMART goals helps the client and family members to recognise small progressive steps during the therapy sessions and how they lead to achieving big goals of activity and participation.

Factors associated with therapeutic goal attainment in children with cerebral palsy: an ambidirectional cohort study

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Introduction: This study aimed to identify factors associated with therapeutic goal attainment in children with cerebral palsy and to evaluate the appropriateness of the set goals.

Patients and Methods: An ambidirectional cohort study, based on cerebral palsy (CP) clinical tracer at the rehabilitation unit of a university hospital, included 109 participants, 52.3 % female, with a total of 463 goals. They voluntarily received therapies using goal-directed therapy and were evaluated by the Goal Attainment Scale (GAS). Clinical information including age, sex, CP type, GMFCS, MACS, CFCS, goals, comorbidities, and number and frequency of therapeutic sessions were gathered and tested for association with the goal attainment.

Results: All participants had a median age of 4.25 years. Most participants (77.8%) were spastic type. The most frequent therapeutic goals for high-functioning participants (GMFCS I-II, MACS I-II, CFCS I-II) were ambulation and hand function, respectively. While the low-functioning groups (GMFCS IV-V, MACS IV-V, CFCS IV-V) concentrated on sitting and swallowing. Overall therapeutic goals were tentatively appropriate with an overall GAS T score of 50.2. GMFCS I-II was the only factor associated independently with goal attainment (odd ratio = 3.026).

Conclusion: The CP children with GMFCS I–II demonstrated a greater chance to attain goals. The GMFCS should be used to guide appropriate therapeutic goals for individuals with CP. The active goals such as improving ambulation and hand function should be set for high-functioning children with CP, while the passive goals such as preventing complications and early motor milestones could be appropriate goals for low-functioning groups.

Relevance for users and families:

Prior to assigning goal-directed therapy for individuals with CP, GMFCS should be used to guide appropriate therapeutic goals in collaboration with the patient's family and multidisciplinary team.

“The effects of backward gait training on the standing and walking skills in children with cerebral Palsy”.

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Some studies support the notion that, already from an early age on (>5 years), Backward walking is organized as the reverse of Forward walking FW, both for arm and for leg movements. Interlimb coordination during FW is largely preserved in BW in children with Cerebral Palsy.

Objective: To investigate the effectiveness of backward gait training on the standing and walking skills in children with cerebral Palsy.

Patients and Methods: 38 children with C.P, mean age 4,5years old, GMFCS I-III, were enrolled and performed rehabilitation treatment for 8-weeks, twice a week. Subjects were randomly divided into two groups: both groups underwent twice a week 45-min sessions of traditional physiotherapy, where the last 20-min performed backward stepping on Litegait (treatment with Body Weight Support Treadmill Training (BWSTT) (experimental group) and overground gait training (Control group).The efficacy of the treatment was evaluated with clinical scales GMFM (D+E). Children were tested at baseline (T0) and at the end of the 8-weeks rehabilitation period (T1).

Results: Both groups experienced a significant improvement in clinical scale GMFM (D+E) for both interventions. We failed to detect any statistically significant differences between groups.

Conclusions: Backward walking training with BWSTT and traditional rehabilitation treatment are both effective in improving standing and walking skills in children with C.P., but longer duration of treatment period and specific assessment tools are needed. Backward walking training with BWSTT may represent an option in C.P children to improve dynamic balance and walking function.

Relevance for users and families:

Backward walking training with BWSTT may represent an option in C.P children to improve dynamic balance and walking function.

The improvement of these skills decreases fear of falling and offers shelf coffidence, required to maximize participation. This is a necessity at home , at school or in the community.

Overmore this increases mobility independence and fullfills the goals of their family.

Increasing participation in the community using early Powered Mobility in Spinal Muscular Atrophy (SMA) Type I. SMAonWheels! 3, 2, 1: The race is on!

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Introduction: The childhood form Spinal Muscular Atrophy Type I has difficulties in reaching motor items such as sitting or independent walking. Early powered mobility would allow changes in the structure and function, activity and participation. The objective is to study the acceptability of an intervention with powered mobility through electric cars for children diagnosed with SMA type I.

Patients and Methods: The study will be carried out in children diagnosed with SMA type I (10 months to 5 years), with less than 7-hours of previous experience with powered mobility. A 12-week intervention (3 s/week) will be carried out in the natural environment with the involvement of the family, and a post-intervention follow-up at 4 weeks. The acceptability and use of power mobility will be evaluated, the functional objectives through the Goal Attention Scale (GAS), participation in the environment with Young Children's Participation & Environment Measure (YC-PEM), functional ability: Pediatric Evaluation of Disability Inventory – Computer Adaptive-test (PEDI-CAT), as well as satisfaction with the use of motorized mobility with Quebec User Evaluation of Satisfaction with assistive Technology (QUEST).

Results: The expected Results would be: demonstrate the feasibility and acceptability of powered mobility in SMA type I, obtain an increase in the child's participation at early age within the community and acquire the functional objectives.

Conclusion: Powered mobility would increase the participation in the natural environment of children diagnosed with SMA type I, favoring different opportunities for their interaction within the community through motivation and learning of functional strategies and family-child-therapist interaction.

Relevance for users and families:

Families will obtain a great learning from the use of powered mobility in the natural environment and the possibility to co-work with researchers in the barriers definitions to remove them and increasing the participation. It will be built a great interaction family-child-therapist. And this research will let the family engagement in research too and co-designing together the next steps for increasing the powered mobility use.

Functional mobility following locomotor training and task specific practice in pre-school aged children with neurodevelopmental disorders: a feasibility study

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Introduction: Optimising engagement during locomotor training (LT) for pre-school aged children can be challenging. We aimed to determine the feasibility of intensive LT embedded within a play-based interdisciplinary framework in pre-school aged children with neurodevelopmental disorders (NDD). Children were included if they required daily physical assistance or equipment.

Patient and Method: Forty-two children with NDD (mean 3.4y, SD 1y;) participated in a LT program (3, 2-hour sessions/week over 4 weeks). Each LT session involved step retraining on the treadmill and overground training in the child's own walking frame. Communication, interaction and functional hand skills development was also embedded within the program. The GMFM-66, Canadian Occupational Performance Measure (COPM), Goal Attainment Scale (GAS) based on activity and participation and 10 metre walk test (10mWT) were assessed at the start of the program (TP1), at the end of the program (TP2) and at 4-weeks follow-up (TP3). Linear mixed models were used to compare within group differences.

Results: There were significant improvements ($p<0.05$) and clinically meaningful changes for COPM, GAS scores, GMFM-66 ($p=0.058$) and 10mWT at both TP2 vs TP1 and at TP3 vs TP1. The program was well attended (mean attendance=24hours) with no adverse events.

Conclusion: Our Results support the feasibility, acceptability and potential efficacy of LT when it is embedded within a play based interdisciplinary environment for pre-school aged children with NDD.

Relevance for users and families:

Relevance for Users and Families: This intervention demonstrates the potential to improve functional mobility in a range of outcomes. Further studies are required to determine effectiveness and longer-term outcomes.

Using a holistic framework to review the impact of lower limb Botulinum toxin A treatment on ambulant children with cerebral palsy

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Background: Botulinum toxin (BoNT-A) is an accepted treatment for temporarily reducing hypertonia in children and young people with cerebral palsy (CYPwCP). Used in conjunction with physical therapy to promote improved function, little is known about its role in improving participation in activities important to children and families. The F-words model sets the International Classification of Functioning, Disability and Health in a child-development context, providing holistic assessment and directing intervention towards meaningful involvement in real-life situations. This prospective single-site study evaluated goal-attainment in ambulant CYPwCP following BoNT-A treatment.

Method: 64 CYPwCP and their families were invited to set up to three goals for their BoNT-A treatment, using the Canadian Occupational Performance Measure to score baseline performance and satisfaction for each goal. Goals were analysed using the F-words model.

Results: F-words analysis of the 169 goals selected showed 33% in Fitness category, (pain, fatigue, splint tolerance, aesthetics, range, selectivity, power, balance, posture); 57% in Function, (predominantly walking related (80), seven ADL goals (dressing, toileting)); 10% in Fun - leisure activities; 1 goal in Friends (engaging with peers).

Discussion: Personalised goal setting allowed families to evaluate performance and satisfaction and provided objective measure of goal-outcome. Families tended to concentrate on areas of Fitness and Function, rather than goals in contexts that reflected participation (Fun and Friends). Although treatment goals frequently referenced walking, only one contextualised "in the playground", improving participation with friends. Exploring why families identify specific goals and investigating how improvements impact their daily lives could help direct a participation focused narrative.

Relevance for users and families:

Goal setting can be a new skill for families, frequently challenging and not always intuitive. Within the clinical setting there can often be a tendency to lean towards a medical model of outcomes. Exploring treatment delivery and potential outcomes within a holistic framework can help children and families identify what is important to them in real-life situations. This ensures outcomes are more likely to be evaluated in terms of meaningful participation and quality of life.

Evaluating the effect of lower limb Botulinum neurotoxin-A (BoNT-A) injections on goal-directed outcomes in ambulant children and young people with cerebral palsy (CYPwCP) using the Canadian Occupational Performance Measure (COPM)

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Background: Identifying meaningful child-and-family-centred goals is an essential element of rehabilitation, ensuring interventions are targeted towards individualised priorities. BoNT-A is used to reduce hypertonia in CYPwCP, with limited evidence on its effect on goal-directed outcomes measures. This prospective-single-site study assessed goal attainment in CYPwCP undergoing BoNT-A treatment using COPM

Methods: Average changes in COPM Performance scores for 64 ambulant CYPwCP (mean age 7y 5mo (SD 2y 8mo) were analysed at 6-weeks, 6 and 12-months post-injection using Friedman tests. Individual goals were classified according to the International Classification of Functioning, Disability and Health (ICF) domains of Body structure and Function (BSF), Activity and Participation (A&P) and Environment (EnV).

Results: Average COPM scores improved significantly ($p<.001$) from baseline across 12-months with improvement at 6-weeks (2.6 (2.1,3)), 6-months (2 (1.3,2.5)) and 12-months post-injection (2.6 (1.7,3.4). These Results suggested clinically significant improvement (minimal clinically important difference of ≥2) at all-time points. 169 individual goals were selected, 57.4% related to A&P, 37.3% related to BSF and 5.3% related to EnV. All ICF goals showed significant improvement at 6-weeks but A&P goals demonstrated the most sustained response to BoNT-A across 12-months.

Conclusions: BoNT-A injections were associated with significantly improved COPM scores at all post-injection time-points suggesting goal attainment in family focused goals. Individual goals evaluated in A&P domains of the ICF showed more sustained improvement across 12-months than those in BSF or EnV domains. Further detailed investigation of the responsiveness within individual ICF domains could help improve the accuracy of evaluating response to BoNT-A treatment.

Relevance for users and families:

Interventions should be evaluated in meaningful terms for children and families beyond a change at impairment level in order to determine whether they improve a childs' functioning, participation and quality of life

Guillain-Barré syndrome after Covid 19 infection and use of Pediatric Evaluation of Disability Inventory (PEDI) in setting and evaluating goals in acute and subacute rehabilitation

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Introduction: Guillain-Barré syndrome (GBS) progresses over several days to weeks, associated with post-infectious autoimmune process, that causes inflammation and myelin damage. Only isolated cases of GBS in children after SARS-CoV-2 (Covid-19) have been described in EU.

Patients and Methods: Thirteen years old patient was admitted to the Children's Clinical University Hospital on 30.03.2021, having progressive tetraplegia, pain in the face, lower back. Radiological and neurological studies showed peripheral demyelinating polyradiculopathy. Recent bacterial or viral infections were excluded, except positive Covid-19 anamnesis before neurologic symptoms occurred, and positive Covid-19 antibody test. Starting rehabilitation, Pediatric Evaluation of Disability Inventory (PEDI) was used.

Results: Acute rehabilitation in neurology department, (04.04.-05.05.2021) for 30 days, physiotherapy (once a day, 6 days a week), occupational therapy (once a day, 5 days a week), speech therapy (once a day, 5 days a week). PEDI self-care 41 points (p.) out of 73, movement 3 p. out of 59; social functions 55 out of 65 p. Subacute rehabilitation department, (05.05.-21.05.2021, 17 days), PEDI: self-care 61 p., movement 13 p.; social functions 55. In July 2021, inpatient rehabilitation for 5 days, PEDI: self-care – 73 out of 73, mobility – 57 out of 59, social functions – 65 out of 65. Walks independently, jumps, runs at a slow pace. Patient continued having physiotherapy in out-patient department, to improve gait to physiological.

Conclusion: Early and continuous rehabilitation reduces functional impairment and disability risks, and improves quality of life. PEDI helps objectifying goal setting and reaching in different aspects of patient's life.

Relevance for users and families:

PEDI helps to monitor person's functional impairment and progress in rehabilitation.

Functional independence is related to dysphagia severity defined by the Pediatric version of the Eating Assessment Tool-10 in cerebral palsy

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Introduction: The aim was to investigate the relationship between functional independence level and dysphagia severity in children with cerebral palsy (CP).

Patients and Methods: One hundred-fifty children with CP participated. The Gross Motor Function Classification System (GMFCS) was used to determine the level of gross motor function. Functional independence level was determined by the Functional Independence Measure for Children (WeeFIM). The presence of open mouth, open bite, tongue thrust, and high palate was scored as absent or present in an observational oral motor assessment. Dysphagia severity was evaluated by the Pediatric version of the Eating Assessment Tool-10 (PEDI-EAT-10).

Results: Children with CP with a mean age of 53 months were evaluated, of which 46.6% were male. The percentages of children classified to GMFCS levels I to IV were 11.8%, 33.9%, 35.4%, and 18.9%, respectively. The median WeeFIM score was 30.The percentages of open mouth, open bite, tongue thrust, and high palate were 33.9%, 24.4%, 29.9%, and 49.6%, respectively. The mean PEDI-EAT-10 score was 20. A low to moderate and negative correlation was found between WeeFIM total score and PEDI-EAT-10 ($r=-0.38$, $p=0.001$).

Conclusion: The study Results indicated that functional independence level was related to dysphagia severity in children with CP. It was suggested that dysphagia severity increased with decreased functional status. Conversely, when functional status of children with CP increased, dysphagia severity decreased.

Relevance for users and families:

Relevance for users and families: This relationship may contribute to select the appropriate dysphagia protocol in children with CP by assessing functional status of children.

Relevance of Goal Setting in Feeding Therapy on the Eating Behavior of children with autism spectrum disorder

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Introduction: Nutrition ensures the overall well-being of an individual. Children with faulty eating behaviors have a detrimental effect on their growth and development. This study thereby highlights the importance of feeding therapy along with pertinent goal setting to incorporate healthy eating behavior.

Methods: The data were collected from feeding therapy reports of 10 children, pre and post-therapeutic intervention. While analyzing these reports, poor eating behavior such as messy eating, picky eating, hyperactivity during meal time, inadequate chewing, poor acceptance of new foods or fruits, lack of self-eating, and food sharing.

Results: Parents were advised to take a 14-day eating challenge after their initial contact. They were asked to introduce their child to solid foods, fix the meal time up to 20 minutes, practice self-eating, and involve them in exploring new foods. It was mandatory that good eating behaviors were rewarded and all tantrums were ignored. It was noticed that after 14 days, 8 out of 10 children had adjusted to the healthy eating patterns well. On average, chewing habits had improved by up to 85%, acceptance towards new foods and fruits enhanced by up to 70%, self-eating had increased by up to 70%, picky eating decreased by up to 60%, food sharing increased by up to 50%, and messy eating had decreased up to 50%. The 2 percent of children who did not benefit from this intervention had a lack of parental support for the cause.

Conclusion: This study focuses on the important aspect of goal setting in feeding therapy.

Relevance for users and families:

RELEVANCE FOR USERS AND FAMILY: Feeding therapy ensures that children with special needs, receive adequate nutrition by following a healthy diet, which leads to proper growth and development.

Parent and child preferences for a community-based physical activity participation intervention for children born very preterm: a qualitative study

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Introduction: Participation in community-based physical activity (PA) provides opportunities for children to be active and develop physical fitness, motor, social and cognitive skills. This is critical for children born very preterm (VP: <32 weeks' gestation) who are at greater risk of motor, cognitive and social impairments, and participate less frequently in PA, compared with children born at term. Intervention to promote community-based PA may provide health and developmental benefits for this group, however little is known about family experiences, or preferences for interventions.

Patients and Methods: This qualitative study used semi-structured interviews to explore experiences of community-based PA from the perspectives of 8–11-year-old children born <30 weeks' gestation and their parents or caregivers. Participants were recruited from the preterm group of a longitudinal cohort study of children born <30 weeks' gestation and at term, recruited from the Royal Women's Hospital, Victoria, Australia between 2011-2013. Data were analysed using the Framework Method.

Results: Interviews were completed with 24 families (5 parent-only interviews, 19 parent-child interviews). Participants were 22 mothers, 3 fathers and 23 children. Themes were developed exploring a) family preferences for a PA participation promotion intervention, b) perceived barriers to PA participation and c) perceived facilitators to PA participation.

Conclusion: Families perceived PA as beneficial for children's health and wellbeing, and felt PA should be fun and provide opportunities for children to succeed. Many families expressed a need for greater access to interventions, resources or programs aiming to promote community-based PA for school age children born <30 weeks' gestation.

Relevance for users and families:

School age children born very preterm and their families experience diverse barriers to community-based PA participation, especially access, availability of programs, financial and social barriers. Many children and families have PA participation goals and may require additional support from health professionals to achieve these. However, our findings reflect the significant socioeconomic environmental impact on community-based participation. Improving inclusive physical activity opportunities will likely need input at a broader policy level.

Treatment of Complicated Clubfoot Using External Fixation: A Scoping Review

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Introduction: The treatment of relapsed, resistant, or neglected clubfoot presents a challenge — some patients may not respond to the traditional Ponseti method. Studies involving gradual distraction using external fixators for treatment of these cases have been performed, but no systematic review has been conducted on the subject.

Patients and Methods: A comprehensive search was conducted of PubMed, Cochrane, CINAHL, Scopus, and Web of Science according to PRISMA guidelines. Only articles that pertained to the treatment of pediatric patients with clubfoot using external fixation and contained three or more human subjects were included. Reviews, professional opinions, and studies with non-human subjects were excluded.

Results: Of 6,469 articles generated from the initial search, 25 met inclusion criteria. 609 total feet (490 total patients) were included, and 533 of these feet (445 patients) were treated with external fixation. The mean age of patients was 8.5 [2-18] years with a mean follow-up length of 40.9 [5-126] months. 21 (84%) studies used the Ilizarov apparatus, two used Joshi's external stabilization system, and one used the Taylor spatial frame. The most reported primary scoring systems were the 60-point International Clubfoot Study Group (ICFSG) score (20%), Dimeglio classification (12%), Pirani score (8%), and Reinker and Carpenter scales (8%). All but one study found significantly improved primary outcomes for the majority of respective patients.

Conclusion: External fixation, which may or may not include open surgery, is a promising intervention for neglected or relapsed clubfoot. Encouraging more standardized outcome measurements would allow for more thorough comparisons between studies.

Relevance for users and families:

Patients who suffer from relapsed, resistant, or neglected clubfoot may have poorer quality of life. Based on published studies, external fixation may serve as an effective treatment for relapsed or neglected clubfoot. This intervention has the potential to reduce time to correction, which would greatly benefit patients and their families.

Functional outcomes after left internal hemipelvectomy and rehabilitation treatment

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Introduction: Musculoskeletal tumors affecting the pelvis are treated, if possible, by internal hemipelvectomy to preserve the lower extremity (LE). However, complications and significant functional loss can occur.

In this study a clinical case who received intensive rehabilitation treatment after undergoing internal hemipelvectomy is described.

Methods: A 15-year-old male diagnosed with Ewing's Sarcoma of the left iliac blade was treated by left internal hemipelvectomy, neoadjuvant chemotherapy and intraoperative radiotherapy.

Evaluation in Rehabilitation department one month later: left LE in external rotation attitude, irreducible hip and knee flexion (20°-40° respectively) due to pain. Active mobility in ankle preserved, proximal absent. Global muscle atrophy.

Results An intensive rehabilitation program was carried out to gain range of motion; progressive strengthening; sitting, transfers, standing and gait re-education. A knee extension splint was prescribed.

Three months later: muscle balance according to MRC scale was 1/5 in psoasiliac, gluteus, adductors and quadriceps; 4/5 in hamstrings and plantar flexors; 3/5 in dorsal ankle flexors. Patient performs autonomous transfers and reaches a stable standing with 2 canes. A 3-cm-raised insole was prescribed for left LE due to a 4-cm dysmetria.

After ten months of treatment: he walks, arises stairs and ramps helped by 2 canes with ulnar support and the raised insole.

Conclusions Even though limb salvage surgery is less aggressive than external hemipelvectomy, such cases are not exempt from suffering functional tumor sequelae.

Intensive rehabilitation programs and high level of motivation from the individual are essential to optimize functional outcomes following an internal hemipelvectomy.

Relevance for users and families:

Intensive rehabilitation programs are essential for cancer patients following surgery and chemotherapy. Our rehabilitation intervention provides them with the maximum possible functionality and independence, thus improving the patient's quality of life.

Intensive multifaceted rehabilitation for a teenage stroke survivor - a case-study showing use of technology and adaptation to achieve participation and self-care goals

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Introduction: This is a retrospective case study of a rehabilitation period for a teenager post stroke, closely linking therapy, orthotic and Botox provision in a technology rich rehabilitation environment.

Patients and Methods: A 14 year old boy, wants to "be normal again" and keep up with his friends. An individual rehabilitation programme was developed with 2-3 hours of therapy a week over 2 months to improve gait and balance. Treatment included orthotics review, Functional Electrical Stimulation(FES), Gait training on land and using Motek C -Mill Virtual Reality Treadmill providing augmented feedback. This was followed by 100 hours over 6 weeks of intensive upper limb rehabilitation based on the Queen's Square Intensive Upper Limb Programme, focusing on daily high repetition intervention and goal orientated training which was adapted to his behavioural and cognitive needs. A variety of sport, game and functional activities were supported by the use of: Saebo glove, Electrical Stimulation, Botox right upper limb, TyroMotion PABLO and the GripAble. Pre and post baseline assessments and outcome measures used included: Canadian Occupational Performance Measure (COPM), Goal Attainment Scaling (GAS), TyroMotion Pablo gait assessment and SiliconCoach movement analysis software, Fugl-Meyer Assessment-Upper Extremity (FMA-UE), 9-hole peg test, dynamometer, video analysis of functional tasks pre-and post-intervention.

Results: There were significant improvements on COPM, GAS, FMA-UE, 9-hole peg test, running speed and functional task analysis.

Conclusion: The intensive multifaceted rehabilitation programme was beneficial in achieving important participation goals and self-care skills. This guides future consideration of developing similar streamlined rehabilitation programmes.

Relevance for users and families:

Providing a streamlined holistic rehabilitation programme where the child's and family's goals are at the centre, reduces disjointed appointments, the amount of service providers, travel and therefore excessive stress on families. It encourages timeliness of specific therapeutic interventions and therefore a better opportunity to achieve challenging goals. In the words of the mother of this teenager "C is now able to do all the things we were previously told he would never do!".

Families and Researchers as Partners: Working Together is Better

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Background: Family engagement in research (FER) advances research relevance to patients' needs and preferences, quality and impact on health care policy and practice. The aim of this infographic is to highlight thoughts and considerations related to FER for establishing equitable partnerships between researchers and partners in the research process to ensure genuine engagement.

Engagement and Methods: An environmental scan was carried out to identify existing knowledge translation strategies related to equitable research partnerships to define and evaluate its integration in research projects. In addition, knowledge about FER was intensified through the certification of the FER course and dialogue groups to consider relevant issues and reduce barriers between partners.

Results: Equitable partnerships is central to meaningful engagement with patient family partners. Authenticity and vulnerability are key to fostering empowering relationships that reflect the interests for people with live experience and researchers. The most important questions to consider when building equitable partnerships includes: Why should we be partners? What is our role in partnership? What do we do in partnership? What should partners expect?

Conclusion: Negotiating the interests and priorities of both researchers and patient family partners in the research process is integral to co-designing interventions with real objectives grounded in the realities of partners.

Relevance for users and families:

allowing families and users involvement from the early phases of the research project and partnering with researchers promotes quality research. It allows users to have a say and lead parts of the project to get Results based on their real perspectives.

Daily upper limb use of children with hemiparesis. Perspectives of families through a qualitative study.

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Introduction: Performance of activities of daily living is fundamental in supporting participation across school, home and community environments and it is a high priority for parents because the lack of them is considered very disabling. Children with hemiparesis often experience restrictions in their participation. The aim of this study is to understand how limitations in the use of the more affected arm influence daily life activities of children with hemiparesis, analyzing the needs and barriers perceived by families.

Patients and Methods: 8 caregivers of children with hemiparesis aged 3-7 years participated in online semi-structured individual interviews. Interviews were recorded and transcribed verbatim. Coding and thematic analysis were carried out by two researchers independently, with subsequent sharing a inter-coders agreement, using Atlas.ti.

Results: The following main thematic categories were drawn from the data analysis: limitations of spontaneous use and impact on daily life activities, child and family strategies to use the arm during routines and most purposeful activities and use of domestic technology. Interviews analysis revealed that bimanual tasks are reduced by a learning-non-used phenomenon as a common child strategy. Families encourage children to use the more affected arm by mainly verbal instructions.

Conclusions: Families are satisfied with child´s performance because of their medical condition but they would like to have more strategies to achieve better outcomes, especially in the integration of the upper limb. Key barrier identified was child´s frustration when comparing with peers. Children enjoy domestic technology as an unimanual activity, but its use is often restricted by parents.

Relevance for users and families:

Taking into account the needs and barriers transmitted by the families of children with hemiparesis, next phases will focus on studying new strategies to address child and families´ needs and to diminish the impact of the non-use of the more affected arm in bimanual activities during daily life.

The Relationship Between Baby-Carrier and Mother's Comfort

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Introduction: Baby-carrier has many functions. One of is to keep baby close to mother, provide babies' comfort and security while allowing mothers to do work. This purpose, comfort levels of baby-carriers were questioned and level of effect on mothers was investigated.

Patients and Methods: Baby-carrier comfort for wearer were inclusion criteria; mothers have between 6-18-month-old babies without any musculoskeletal problems and neurological deficits and being able to participate in questionnaire shared over internet. Baby-carrier comfort was evaluated by Visual Analogue Scale-(VAS) on maternal health.

Results: A total with mean age of 34.33 years, 75% unemployed women, met inclusion criteria, and their duration of using baby-carrier was 5,45 months. Mean age of babies (50%-boys) was 10.5-month with 37-gestational-week. Mean birthweight of babies was 2812-gr, current weight is 8816-gr. Considering mothers weight; as 67.75-kg before pregnancy, gained 13.41-kg during pregnancy, and current weight is 74.66-kg. In the VAS, mother-baby accordance was 7.11/10, baby-carrier comfort was 6.33/10. While there was significant relationship statistically between baby-carrier comfort and mother-baby accordance (p=0.011), no relationship between baby-carrier comfort and mothers' weight (p=0.077), current babies' weight (p=0.403).

Conclusion: As a Conclusion, it was found that mother-infant accordance was associated with baby-carrier comfort, but it's not depending on characteristics such as gaining weight. In recent studies, comfort of baby-carrier is due to an even distribution of child's weight that load to wearer's spine, and carrying capacity of baby-carrier and closeness of weight of mothers gaining during pregnancy to child's weight.

Relevance for users and families:

Baby's weight should not exceed 20% of body weight, to use an alternative approach to be used such as baby cart to carry baby for long durations when the baby's weight exceeds 10 kg.

Conducting research on transitioning to adulthood for young people with special educational needs and disabilities (SEND): What do parents of young people with SEND with diverse needs think?

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Introduction:Transitioning to adulthood is an important developmental milestone. However, despite legislative changes in the UK in the past decade, young people (YP) with SEND and their families continue to experience exclusion, support service fragmentation, and employment barriers. Participatory action research (PAR) is a method of researcher-participant co-production aiming to deliver research and subsequent societal change that benefits those to whom the research is most relevant. However, user-informed research in this field is lacking.

Methods:We applied PAR to developing a research agenda concerning the adulthood transition experience in SEND. We conducted 2 PAR forums with parents of YP aged 18-25 years with diverse SEND needs in a South-East London area (UK) to 1) identify optimal approaches to the required research process and 2) identify research priorities. 19 parents/carers participated, with 2 discussion groups per forum. Views were recorded in keeping with a user-centred, power-balanced approach, and collated into themes corresponding to the forum objectives.

Results:Relating to 'research process', sub-themes of 'parents' voice 'and 'young person's voice' highlighted opportunities and challenges in capturing relevant perspectives, especially for YP with more complex communication needs. Within 'research priorities', participants outlined key 'barriers and concerns', including what constitutes a 'successful transition experience'.

Conclusions:Involving parents of YP with SEND in researching the topic directly relevant to their lives allowed identification of key research questions of concern to affected families. Future planned activities with YP themselves will further ensure that our current research accurately represents the needs and priorities of those to whom this research matters most.

Relevance for users and families:

Involving relevant stakeholders in co-producing research that directly concerns them is key to ensuring that this research accurately addresses their needs and concerns. Using participatory action research principles, we report findings from consultations with parents/carers of young people with diverse SEND needs, which helped identify key priorities concerning our research on transition to adulthood of affected young people, from the perspective of their parents who frequently have to advocate on their behalf.

Characteristics of the implementation of the CO-OP program and its effectiveness: a pilot study

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Introduction: Focused on enabling success, the CO-OP ApproachTM employs collaborative goal setting, dynamic performance analysis, cognitive strategy use, guided discovery, and enabling principles. These elements are situated within a structured intervention format. As a part of larger international research, we were interested in how CO-OP licensed occupational therapists implement this approach. Further, we wanted to evaluate the efficiency of CO-OP program to improve selected children's goal activities and which tests are used by the therapists.

Patients and Methods: We collected data on eight CO-OP licensed therapists through a questionnaire prepared for this occasion and retrospectively on 35 children, who participated in CO-OP program at University rehabilitation institute of Republic Slovenia and United Kingdom. Performance and satisfaction with performance was evaluated with COPM; quality of performance with PQRS.

Results: All therapists used CO-OP ApproachTM recommended evaluation instruments and follow the required protocol of work. They believe, the approach is effective in enabling children to acquire new skills and see their progress. 35 children (mean age 8.6 years, 48% with developmental coordination disorder, others with cerebral palsy or other diagnoses) attended in average 9.6 sessions, usually once a week. They've chosen 31 different goals. Analysis of showed significant improvement of performance/satisfaction and quality of performance (mean COPM scores from 4.2/5.1 to 8.3/9.0; mean PQRS scores from 4.0 to 8.2) ($p<0.01$).

Conclusion: Results confirmed the CO-OP ApproachTM to be efficient in improvement of performance of chosen activities and their quality. Therapists reported to follow and execute all elements of approach in therapy programs.

Relevance for users and families:

The CO-OP ApproachTM is effective in the rehabilitation program in improvement of performance and satisfaction with performance of selected goal activities. By understanding of how licenced occupational therapists are following the CO-OP structured intervention, we might adjust the education process and better support the execution of program in clinical setting.

A composite index of salivary metabolites and observational variables to assess pain in people with cerebral palsy and communication disorders

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Introduction: Pain in people with cerebral palsy (CP) is underestimated, particularly in individuals with impaired communication skills. The goal of this study is to analyze in a composite index the changes in different salivary metabolite levels and in observational pain scales, before and after a painful procedure in adults with CP and adults with typical development (TD).

Material and Methods: Thirty adults with CP and 30 adults with TD participated in a painful procedure (intramuscular injection). Participants were video-recorded during the procedure and different observational scales (EVA, NCAPC, FACS) were scored off-line. Salivary samples were taken 10 minutes before and 10 minutes after the injection and metabolite levels of cortisol, TNF-α, ADA, IgA, sAA and FRAP were analyzed. A Composite Index grouped these variables into 4 categories: Observational markers (EVA, NCAPC, FACS), Neuroendocrine markers (Cortisol), Immune markers (TNF-α, ADA, IgA), and Oxidative stress markers (sAA, FRAP).

Results: The CI was higher in individuals with CP than in individuals with TD. Both groups increased the index after the injection, except for the neuroendocrine category, which remained stable. The stable levels of cortisol could indicate that the procedure was not stressful, but painful, both for individuals with CP and TD.

Conclusions: The CI can show equal changes in adults with CP and adults with TD, at low pain intensities and in early times (10 minutes post-stimulus). Scores in the different categories may differentiate pain from stress, what makes it a useful tool to measure pain in individuals with CP and communication disorders.

Relevance for users and families:

A composite index combining salivary metabolites and observational scales may be a reliable tool for detecting pain, even of short duration and at low intensity levels in individuals with cerebral palsy and communication impairments.

Hip pain in neuromuscular disorders, a proposal

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Introduction: Neuromuscular hip disorders are disorders of the hip caused directly or indirectly by neuromuscular pathologies. Muscle imbalance around the hip caused by an underlying neuromuscular disease can lead to subluxation and dislocation of the joint in growing children and can cause pain and disability.

Patients and methods: Regarding the muscular hip approach, there are certain differences between spastic and flaccid forms which have to be specified. We include in our sample children with cerebral palsy and spinal muscular atrophy wich suffer from hip pain.

Results: A combination of 3 techniques is proposed for painful spastic hip (in cerebral palsy), and in hip pain associated with SMA, with different goals.

- INTRA-ARTICULAR HIP BLOCK
- BLOCKING + Pulsed Radiofrequency Nerve OBTURATOR
- botulinum toxin targeting the spastic muscles involved in the dislocation (iliopsoas, rectus femoris, medial hamstrings and adductors).

We describe the techniques and the Results obtained in our patients.

Conclusion: Hip deformity in children with disability leads to pain and loss of mobility and function. One in three children with cerebral palsy will have a hip dislocation. The highest risk is in the non-ambulatory population, GMFCS levels IV-V. Pain associated with hip deformity is a major cause of progressive deterioration in quality of life over time. In patients with spinal muscular atrophy, different locomotor system complications appear due to severe hypotonia and muscle weakness, among which hip subluxation or dislocation stands out due to its frequency. Pain is observed in the evolution time from subluxation to dislocation.

Relevance for users and families:

Neuromuscular hip treatment has two objectives:

- to avoid contractures and
- if the dysplastic hip becomes painful or if sitting and perineal care is difficult due to contractures, to perform rescue procedures to improve function and eliminate pain.

This will improve the quality of life of the children and their families.

Zoledronate increases bone mineral density in non-ambulant children with cerebral palsy: A randomized, controlled trial

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Introduction: Low bone mineral density (BMD) is prevalent in children with cerebral palsy increasing fracture risk and compromising an optimal bone health trajectory through the lifespan. Zoledronate is increasingly used to improve the BMD, however, no randomized trial has evaluated the effect. We performed a multi-center, randomized, controlled, double-blind trial to evaluate the effect of zoledronate in children with non-ambulant cerebral palsy.

Patients and Methods: Two doses of placebo or zoledronate were infused at a 6-month interval. Dual X-ray absorptiometries of the lumbar spine and lateral distal femur were done at baseline and 12 months and the BMD Z-score changes were calculated. Growth was monitored using weight, bone age, pubertal staging, knee-heel length and blood biomarkers.

Results: Twenty-four participants were randomized and completed the study. Ten were treated with placebo. The fourteen participants in the zoledronate group experienced BMD Z-score gains of +0.8 SD at the lumbar spine and +0.3 to +1.7 in the three regions of the lateral distal femur. Three of four gains were significantly different from the placebo group. Moderate to very severe influenza-like symptoms were common in the zoledronate group, but only after the first dose. Lasting side effects including growth changes were not encountered.

Conclusion: Zoledronate significantly increases BMD in children with cerebral palsy in one year without affecting growth. First-dose side-effects were common and considerable. Studies into lower first doses and long-term outcomes are needed.

Relevance for users and families:

A low bone health reduces the wellbeing of persons with cerebral palsy due to a higher risk of fractures, bone pain and deformities. Further, fractures are associated with increased mortality. We performed a drug trial and found that two doses of zoledronate increases the bone mineral density in non-ambulant children with cerebral palsy. This reduces the fracture risk and may benefit the lifetime bone health, but the first dose often has severe influenza-like side effects.

Investigation of The Relationship Between Pain and Clinical Factors in Children with Cerebral Palsy

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Introduction: Pain is a common problem in CP. Therefore, our aim in our study is to examine the relationship between pain and clinical factors in children with CP.

Patients and Methods: Our study included 103 (44 female, 59 male) children with cerebral palsy aged 8-17 years (11.81±3.22 years, BMI: 19.08±3.07). Children's demographic information, clinical types, and extremity involvement were recorded in the data form, their pain status was evaluated with Visual Analog Scale (VAS) and Child Health Questionnaire (CHQ) - Parent Statement Form, questions in the pain section, their functional status was Gross Motor Function Classification System (GMFCS). measured with.

Results: When the relationship between pain status and clinical factors in children with Cerebral Palsy was examined, a moderate positive correlation was found between GMFCS and pain ($p<0.05$). Apart from this, no significant relationship was found between clinical type and extremity involvement and pain ($p>0.05$).

Conclusion: The Results of our study show that there is a relationship between pain in children with CP and the functional status of children. Pain due to different reasons in children with CP negatively affects the social life, activities of daily living and functional status of the individual. Our Results show that treatment programs for the detection and prevention of pain are a very important factor in children's gaining functional independence in daily life and increasing their health-related quality of life. More studies on pain are needed in the rehabilitation of individuals with CP.

Keywords: CP, VAS, GMFCS, Pain

Relevance for users and families:

Pain is a common problem in CP. Pain due to different reasons in children with CP negatively affects the social life, activities of daily living and functional status of the individual. As we mentioned in our study, it is closely related to the functional status of children. This, in turn, affects the quality of life and negatively affects their treatment. In the treatment of children, applications for pain should be added to the absolute.

Gastro-Intestinal Dystonia in children with Severe Neurological Impairment

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Introduction: GID consensus statements were developed in 2022 by the British Society of Paediatric Gastroenterology Hepatology and Nutrition (BSPHGN). These provided a foundation for further evidence based guidelines for children with GID who would benefit from a palliative care approach.

These new guidelines were needed due to an increasing number of complex children with evolving GI symptoms and pain associated with feeds: presenting with significant distress; impacting on quality of life; leading to multiple investigations, medications, and

hospital admissions.

Patients and Methods: To develop the first evidence based guidelines for assessment and management of children with GID who would benefit from a palliative care approach.

Results: A systematic review was performed with Cochrane support. 1399 unique abstracts were screened. Of these, 53 full texts were reviewed and 52 excluded; 1 case report was identified. It was not possible to use GRADE approach due to no studies identified. The group identified additional supporting indirect evidence that was considered useful to guide discussion around recommendations. The group also developed guidelines into the assessment and management for GID from the direct/indirect evidence and consensus opinion.

Conclusion: Clear recommendations for assessment of GID (pain, upper GI, and Lower GI predominate symptoms) through non pharmacological and pharmacological management and end of life care. Discussion of which medication to use, when and for what indication, plus advice on optimising symptom management in GID. Produced guidelines which are available open source. They will be updated in 3 years time.

Relevance for users and families:

GID is a new diagnosis but the consellation of symptoms and the effects on children and families isn't. Professionals have struggled to manage the symptoms with little evidence and guidance to support clinical practice. These are the first guidelines to aid clinicians to support these children with GID.

Hope is that it will help with symptom management and improve the quality of life of children and families due to the implementation of the guidance.

Is it the device or the way we use them? A pilot study to assess the effects of different levels of screen brightness and font sizes on accommodation.

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Background: The entire eyecare world is talking of increase in myopia and the deleterious effects of using devices like computers and mobiles. Devices have been blamed for the increase in myopia among children. The question that comes to mind is, "is it devices that are to be blamed or the way we use them?" This study was conducted to see the effect of changes in screen brightness and font sizes on accommodation.

Methodology: 50 young adults (25 males and 25 females) were subjected to 3 levels of brightness and 3 different font sizes on the screen of a computer. Accommodation was evaluated using WAM 500 open field autorefractor with these levels. The subjects were required to read the text while the evaluation was performed. All the readings were taken in ambient room illumination and the dark room.

Results: In all the subjects accommodation exerted was more in reduced brightness of the screen and with smaller font sizes. They also accommodated less in ambient room illumination. All the Results were found to be statistically significant.

Conclusion: This was a pilot study to analyse accommodation differences. It is clear from this study that the way we use the devices are more significant rather than just using them. This study endorses further research into ideal suggested brightness ranges as well as ideal font sizes. These suggested ranges would be path breaking to ensure healthy use of devices.

Relevance for users and families:

Highly relevant with an increase in myopia throughout the world.

A specialist clinic for children with Down Syndrome: effective use of limited clinical resources.

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Statement of Problem: Down Syndrome (DS) is the commonest chromosomal disorder worldwide and Ireland has the highest rate in Europe. DS is associated with significant medical co-morbidities and children require annual health surveillance. Historically in Dublin, access to paediatric care differed according to the home address with some children attending community based clinics with no access to phlebotomy, audiology or radiology.

Description of the product: The clinic for Children with DS was established in 2015. Initially a nurse led clinic it has expanded to include a Consultant paediatrician and neonatologist. The Clinic allows full health assessment including, history, physical examination, blood tests, and audiology or radiology when required. A comprehensive proforma has been developed to support junior doctors in the clinic and ensure adherence to published national and international guidelines.

Findings to date: Staffing includes 1 WTE clinical nurse specialist (CNS) and 0.1 WTE consultant paediatricians. Over 320 children are supported. Face-to-face Clinics are held twice monthly. In addition, 2 virtual clinics each month allow rapid response to abnormal Results and urgent telephone reviews . The CNS does 40 new baby consults and responds to over 2,500 telephone or emails queries annually. The clinic has a research component, with 3 completed PhD degrees and over 10 publications to date.

Practical Applications: This clinic model demonstrates efficient use of limited clinical resources. The CNS provides responsive and expert support to a large clinical cohort. Consultant paediatricians are available for additional clinical support when required. Satisfaction with the service is high.

Relevance for users and families:

This clinic meets the healthcare needs for children in a child-friendly, holistic manner. The staff involved are knowledgeable and provide consistent and reliable access to clinical advice. Satisfaction with service has been evaluated and is high.

Enabling children and young people with intellectual disabilities to express their views on their inpatient hospital experience

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Introduction: The importance of enabling patients to provide feedback about their health care is widely accepted but development of appropriate measures to ensure inclusion of all patient groups has not kept pace, particularly for children and young people (CYP) with intellectual disabilities (ID). Although increasing numbers of CYP with ID access hospital care every year, they are rarely, if ever, directly asked about their healthcare experiences, partly due to lack of appropriate measures to enable them to meaningfully express their views.

Patients and Methods: A hospital inpatient PREM previously developed for children aged 8-11 years was revised iteratively in conjunction with a parent advisory group and CYP with ID. The PREM was tested on children's wards in seven hospitals over a three-month period.

Results: Parents suggested one PREM for all CYP with ID, simpler language, fewer questions and response options and images to illustrate each question. Seven children provided feedback on the images. The final PREM had 22 questions, each with a corresponding image. Questions addressed environment, people, care and treatment, and safety. Testing with 47 CYP with ID (4-18 years) resulted in few missing data. Challenges to completion were linked to the optimum number of response categories.

Conclusion: The development of a PREM for CYP with ID provides a previously unavailable opportunity for them to report on their experiences of inpatient care. Future work to extend testing to a wider group will enable us to clarify whether one PREM is valid and reliable for all CYP with ID.

Relevance for users and families:

Developing a patient reported experience measure for children and young people with intellectual disabilities has offered them an opportunity to have their voices heard with regard to their inpatient hospital experiences. Knowledge about how care is perceived by children and young people with intellectual disabilities will help service providers to meaningfully improve what they do and how they deliver care.

Exploring Children and Families experiences of Botulinum Toxin A treatment. Do standardised clinical outcome measures reflect changes that children and families consider important?

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Background: Botulinum toxin-A (BoNT-A) is an established treatment to reduce hypertonia in children with cerebral palsy . However, the perspectives and experiences of parents and children remain largely absent. This study aimed to explore experiences of BoNT-A treatment from the perspective children and their parents and to establish how well standardised clinical outcome measures reflect their experiences.

Methods: Semi-structured interviews were conducted with 18 children and parents, using topic guides centred around ICF domains. The mosaic approach, utilising creative Methods, gathered information from children. Purposive sampling strategies were employed to gain insight into different perspectives. Qualitative data using verbatim transcripts was analysed using a reflexive thematic approach.

Findings: Two overarching themes of uncertainty and anxiety were derived from qualitative analyses of parent data, which related to drivers for BoNT-A treatment, engagement with professionals, impact of treatment, expectations and outcomes. Children's perspectives focused on, wanting to keep up with their peers. Whilst the injection procedure caused varying degrees of discomfort, children described positive changes in confidence participation following treatment.

Conclusions: Families described BoNT-A treatment as providing an opportunity to improve function, which improved children's confidence and increased opportunities for participation with peers. Improved confidence and self-esteem were not evaluated by standardised outcome measures. Families were realistic about the magnitude of change to expect post BoNT-A and were keen to discover ways to potentiate the effects of treatment with adequate rehabilitation following injections. The study highlighted uncertainty about long-term effects of BoNT-A and concerns about the painful nature of the injection procedure.

Relevance for users and families:

The perspectives and experiences of parents and children rare rarely heard when discussing the outcome of interventions for children and young people with cerebral palsy. This study asked families how well clinical outcome measures reflected their experience of Botulinum toxin-A treatment, as well as asking the children about their own experience of treatment. The Results highlighted the importance of evaluating treatment in terms of meaningful outcomes such as change in function and confidence and self-esteem.

Evidence for birth-related post-traumatic stress and quality of parent-child relationship in the first two years of life. A systematic review

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Introduction: Research has predominantly focused on postpartum depression (PPD) in parents. Evidence suggests that poor-birth mental health in mothers negatively affects the quality of mother-child relationship.

Aims: To systematically review the current evidence for an association between parental childbirth-related PTS and PTSD and indicators of the quality of the parent-child relationship during infancy.

Methods: A systematic review was performed using PsycInfo, CINAHL, Medline and Web of Science databases to identify papers. Reviews and Meta-Analyses (www.prisma-statement.org) guidelines were followed. Screening of abstracts and full papers was completed for 2413 papers. Quality assessment was undertaken using the "Strengthening the reporting of observational studies in epidemiology" (STROBE).

Results: Twenty-four papers were included in this review. Study design varied; there were 11 cross-sectional and 13 longitudinal studies. Although there is some evidence that suggests that birth-related PTS may have an impact on the child-parent relationship, findings across studies were mixed. Other indicators of parental postpartum psychological distress and parental factors may also be predictors of the parent-child relationship than distress specific to the birth experience. There was no evidence from the papers reviewed, the effect of maternal PTS on child development.

Conclusion: To our knowledge, this is the first review to summarise the evidence for the association between birth-related PTS symptoms and parent-child relationship quality. There is some indication that increased parental birth-related PTS is related to poorer parent-child relationship quality. Further work should assess the relationship between increased parental birth-related PTS related to poorer parent-child relationship quality and the impact on child development.

Relevance for users and families:

The main aim of the review is to have a better understanding of the difficulties that families may experience after a traumatic birth so that healthy early relationships can be build. This will lead to better outcomes for the child and the rest of the family.

Barriers and facilitators to the implementation and sustainability of the "ENabling VISions And Growing Expectations" (ENVISAGE) program for parents of children with developmental disabilities in Croatia

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Introduction ENVISAGE is a 5-week online empowerment program for parents of children with developmental disabilities (DD) (0-6 years), recently translated and adapted to a new language and cultural setting, Croatia. The objective was to learn about relevant barriers that could impede the program's short- or long-term success and facilitators that could support its implementation and uptake.

Methods Data was collected as part of a mixed-method study that explored the transferability of ENVISAGE . We engaged parents with lived experience and professionals working with families of children with DD. The Results were derived from the qualitative data subset and were analyzed using inductive qualitative content analysis.

Results Thirteen participants completed the qualitative data collection (5 parents, 7 professionals). We identified five groups of barriers: (1) individual-level (e.g., lack of motivation, low literacy), (2) group-level (e.g., lack of trust between attendees and attendees and facilitators), (3) societal-level (e.g., the social stigma of having a child with DD, low socioeconomic status), (4) attitudinal (e.g., lack of trust toward 'systems'), and (5) technological (e.g., low digital literacy, Internet and technology access). Identified facilitators included: (1) individual-level (e.g., early adopters will see the value in it and spread the word), (2) group-level (e.g., small groups, peer exchange), and (3) program-level (e.g., online mode of delivery, parent-professional co-facilitation) facilitators.

Conclusions Some key barriers and facilitators should be considered when implementing ENVISAGE in Croatia. Addressing them will help for ENVISAGE to become a widely accessible program for parents of children with DD in Croatia.

Relevance for users and families:

When implementing a novel intervention for children/families, it is critical to identify factors that could promote or impede implementation. In this study, we aimed to identify facilitators and barriers for a new empowerment program ENVISAGE for parents of children with DD in Croatia. Safe, effective and feasible implementation will be strengthened by building on the program's strengths and addressing barriers throughout the research process.

Five-To-Fifteen at 5 years and developmental coordination disorder at 11 years in children born very preterm

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Introduction: Children born very preterm have an increased risk for motor impairments such as developmental coordination disorder (DCD), which in turn is associated with adverse cognitive development and lower self-experienced quality of life. We aimed to evaluate whether parental questionnaire Five-To-Fifteen (FTF) identifies children who have an increased risk for later DCD.

Patients and Methods: This study is a part of the PIPARI Study, a prospective follow-up study of children born very preterm (gestational age <32 weeks and/or birth weight ≤1500 grams) in 2001-2006 in Turku University Hospital, Finland. Neurodevelopment at 5 years was assessed by parents using the FTF. The Movement Assessment Battery for Children – Second Edition (Movement ABC-2) was performed to assess motor outcome at 11 years. Percentiles for total test scores ≤5th percentile denoted DCD.

Results: 133 children born very preterm were included, and 13 (9.8%) had DCD. Higher scores (more problems) in the FTF Motor skills and Perception correlated with lower total test scores (more problems) in the Movement ABC-2 ($r=-0.38$, $p<0.001$, and $r=-0.23$, $p=0.007$). Children with DCD had higher median scores in the FTF Motor skills (0.50 vs. 0.19, $p<0.001$) and Perception (0.36 vs 0.14, $p=0.003$) compared to children without DCD.

Conclusion: The FTF may be useful additional tool in identifying children born very preterm in increased risk for later DCD and its comorbidities.

Relevance for users and families:

The use of the FTF might be cost-effective method to allocate timely interventions and support for children with an increased risk for motor impairment.

A feasibility study looking at the use of sensory bedding in children with ASD

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Introduction: Up to 90% of children with autism spectrum disorders (ASD) have sleep problems, affecting quality of life. This feasibility study assessed a sensory compression sheet to improve chronic insomnia in ASD.

Methods:

Design: Mixed Methods study within child cross-over design.

Setting: Southampton and Sheffield Children's Hospitals (UK)

Children with ASD, chronic insomnia and high sensory seeking scores (Short Sensory Profile) were studied for two weeks in each type of sheet (sensory and usual bedding) randomised to first order. Sleep was characterised at baseline by the Child Sleep Habits Questionnaire (CSHQ) and objective actigraphy during the second week of each sleep condition. Differences in total sleep time (TST), and sleep efficiency (SE) were assessed. Thematic content analysis of parent interviews informed feasibility.

Results: Forty-four families were contacted for achieved sample of 20. Nine were ineligible, fourteen did not complete screening and three withdrew. Ten of eighteen children (5 -12y, 7 male) have completed the study. Eight children had CSHQ total sleep disturbance scores above the clinical threshold (>41, range 43-68). Actigraphy data were complete for six: mean TST was significantly longer in sensory bedding v usual bedding {7.4h (6.5-8.3) v 7.0h (6.2 – 7.5), $p < 0.046$}. SE did not differ between conditions (sensory bedding 81.4%, usual bedding 80.5%). Preliminary emerging themes consider autonomy, environment and technology implementation. Complete data will be available in December 2022.

Conclusion: Preliminary findings suggest improvement in total sleep time with sensory bedding. Study design was feasible although recruitment, retention and adherence were challenging.

Relevance for users and families:

Chronic insomnia is erosive to family and child wellbeing. Simple sleep solutions for sensory seeking children, such as sensory bedding, are of potential value and may help chronic insomnia in ASD children. This preliminary data offers insights into both the potential for sensory bedding to help sleep in selected children and insights into fully powered trial design.

The Covid-19 pandemic lockdown restrictions: a qualitative perspective of the impact on children's self-care

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Introduction: The inability to carry out self-care activities has a significant impact on a person's health, wellbeing, and participation in society. Early years of life are a period particularly sensitive to stress, with known negative impacts both on the health and wellbeing of children. The global COVID-19 pandemic, and the associated lockdown measures have been a new, extreme stressor affecting most of the world population, and little is known about how it impacted on children's participation in daily activities and their self-care independence. This study investigated the impact of COVID-19 containment measures on children's self-care, and their parents' response to this.

Patients and Methods: This qualitative study explored two UK-based online parent discussion forums, and targeted posts in relation to children's self-care during the pandemic between March 2020 and July 2021. This included feedback from parents with children aged 0-18 years. A discourse analysis approach was used to analyse parent responses, and in particular their choice of response.

Results: Evidence was found that the lockdown had a negative impact on some children's self-care, and their parents' wellbeing. For example, parents stated that dealing with their child's difficulties was a 'battle'.

Conclusion: The findings from this study will help health-care professionals understand the effects of the Covid 19 containment measures on children's participation in self-care (activities of daily living). The findings from this study will also enhance therapists' and health care professionals' understanding of stressors influencing self-care in children, and the impact on their families.

Relevance for users and families:

This piece of research shares the lived experience of parents talking about their children's self-care difficulties during the pandemic. It may helpful for other parents to learn more about this and provide solidarity to those who had similar experiences during the period of the Covid 19 lockdown restrictions.

The effectiveness of Group Therapy for children with Autism

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Introduction: Autism refers to a range of conditions characterized by challenges with social, communication skills and repetitive behaviors. Current treatments for autism seek to improve daily functioning and to improve quality of life. These treatment plans usually involve multidisciplinary input either given individualized session or group session. Group therapy mainly focused on training of social and communication skills and functional activities in children with autism.

Patients and Methods: This study has been conducted in a Kolkata based Child Development Center (CDC). 56 children with Autism, age group between 3 to 16 years are selected and equally divided into two group (Group A and Group B). Both group has undergone parental training program of one week. Children of both group assessed with standardized assessments (ADOS2 and Griffiths) prior to intervention. After assessment Group A has been assigned CDC based multidisciplinary intervention for 12 weeks and Group B has been given therapist delivered Group therapy for 12 weeks. Both the group has been evaluated by Pediatric Evaluation of Disability Inventory-Computer Adaptive Test (Autism Spectrum Disorders) (PEDI-CAT (ASD)) and Autism common brief International Classification of Functioning (ICF) Coresets at baseline and after 12 weeks of intervention.

Results: Both Group A & Group B showed improvement but Group B shows better improvement than Group A in Social/Cognitive and Responsibility domains. Group B also shows better outcome in Activities and Participation section of ICF.

Conclusion: Group Therapy is better mode of intervention to improve daily activities, social &cognitive abilities and responsibility in children with ASD

Relevance for users and families:

Group therapy teach children learn how to behave in a social situation. They can learn about the importance of friendship and companionship and Improve their social participation. The development of social skills can help them to be successful in academic and vocational settings. It develop their empathy, helping and sharing skills. Increase participation in recreational activities.

Lung ultrasound for aspiration detection in infants and young children with neurological disorders

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Statement of problem. Children with neurological impairment experience abnormal ingestion functions (WHO,http://apps.who.int/classifications/icfbrowser/), that predispose aspiration-induced lung disease, malnutrition, further neurodevelopmental disturbances, and stressful interactions with caregivers. Infants who are not clinically suspected of dysphagia or GERD may have silent aspiration. Videofluoroscopic swallowing study (VFSS), and fibre-optic endoscopic examination of swallowing (FEES) are available, with limitations at earlier ages, and due to rheological property of barium-impregnated liquids. Earlier diagnosis enhances clinical management ad tailored rehabilitation strategies to improve outcome and limit short- and long-term complications.

Description of the product or technology. Lung ultrasound (LUS) reached consensus as a non-invasive, radiation-free tool for the diagnosis of acute and chronic pulmonary conditions at any age. Previous studies demonstrated that LUS detects minimal lung consolidations with very high and dynamic accuracy. LUS is a patient-friendly tool, especially in young children, who are particularly susceptible to radiation exposure.

Findings to date. In preschool children with neurological disorders, we coupled LUS with a typical meal of the child. Exploratory Results support the feasibility of LUS in the clinical setting, showing lung abnormalities likely related to abnormal ingestion function, with potential benefits over assessment and management of complex care of children with severe neurological disorders. A clinical trial on this LUS application (ClinicalTrials.gov Identifier: NCT04253951) is ongoing.

Practical applications. LUS coupled with feeding requires a simple ultrasound equipment and a basic training. LUS relatively simple semeiotic has been applied to other general populations and translated to different professionals including medical doctors, nurses, speech and language pathologists.

Project funded by Italian Ministry of Health, Bando Ricerca Finalizzata 2018 GR-2018-12367809.

Relevance for users and families:

Acute and chronic pulmonary complications due to swallowing disorders are common in infants and young children with neurological impairment, including aspiration. LUS is a cost-effective, easy, fast, safe, radiation-free tool for the diagnosis of many lung conditions. LUS use for feeding monitoring improves detection of aspiration and multiple outcomes in infants and young children with neurological disorders. Results might be translated to low-resources settings.

Big data acquisition to establish machine learning for automated motion detection in early infancy using 3D computer vision

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Statement of problem: Early interventions (EI) can improve outcome in children with neurodevelopmental disorders (ND). Screening for the risk of ND relies on the expertise of trained pediatricians. Establishing computer vision-based machine learning algorithms could objectify referral to EI at a very early age.

Description of the product: We established a markerless 3D computer vision-based skinned multi-infant linear (SMIL) model which generates a digital full body shape of freely moving infants with high precision (scan to mesh distance 2.51mm; SD 0.21mm) and high resistance to pose errors (accurate pose estimation in 98.8% of recording time).

Findings to date: Based on SMIL, we demonstrated, that human expert-based assessment of general movements (GMA) using 3D digital full body motion videos is equally sensitive and specific to detect definitely abnormal general movements as conventional GMA. Objective motion parameters could be extracted from SMIL with high precision to quantify infant movements apart from GMA. We showed that SMIL-based full body motion analysis highly correlates with clinical CHOP INTEND scores in infants with Spinal Muscular Atrophy.

Practical application: After study registration (DRKS00029247) we have started to collect 3D videos of infants up to 20 weeks corrected age. We will correlate >120 patient-specific clinical parameters with motion characteristics derived from SMIL in 2.000 infants with or without increased risk of ND. We aim to develop and test machine learning algorithms on "the assessment of typical motor development" in early infancy and on "automated GMA".

Relevance for users and families:

Users: RGB-D Data may be sharable in the future for joint research projects in the field of automated motion analysis in infancy.

Families: using artificial intelligence-based motion analysis in infancy, families will have access to objectively detect ND in population based screening setup in industrialised as well as developing countries to ensure appropriate inclusion into early intervention programs.

Development of a complex neurodevelopmental disorders assessment pathway within acute hospital paediatric neurodisability service

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Statement of problem: A paediatric hospital neurodisability service had access to specialist assessment from speech and language therapy, child psychiatry and clinical psychology departments. Waiting lists for each of these services were held separately and assessments were not coordinated across these disciplines. This led to diagnostic delays and overlap in assessment processes.

Description of the product or technology: A pathway for a coordinated specialist assessment service was required to maximise resources, integrate multidisciplinary clinical expertise and facilitate evidence based differential diagnosis in complex presentations in a timely manner. A distinct multidisciplinary referral, triage, assessment and feedback process was developed. The assessment process included: multidisciplinary intake sessions; coordinated assessment plan; separate and joint diagnostic work up with the multidisciplinary team to determine differential diagnosis; and feedback process with parents (and child as appropriate).

Findings to date: An evaluation of the pathway is ongoing. Preliminary findings indicate that coordinate of multidisciplinary resources resulted in timely diagnostic Conclusions and referral onwards for intervention in community services.

Practical applications: This pathway serves as a model for specialist assessment of complex neurodevelopmental presentations within a paediatric hospital neurodisability service. The authors recommend this pathway should be incorporated into the clinical operating model for paediatric Neurodisability in the new National Children's Hospital in Ireland

Relevance for users and families:

Parents often cite the frustration of receiving separate uncoordinated and sometimes contradictory assessments. This work demonstrates the particular benefit of timely, coordinated multidisciplinary assessment for children with complex neurodevelopmental presentations.

Age adequate movement repertoire in a large population-based cohort

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Introduction: Within the Motor Optimality Score of Prechtl's General Movement Assessment (GMA), the adequacy of the movement repertoire is determined the by observation of age dependent movement patterns of the infant at the time of assessment. Reported rates for age-adequate movement repertoire in low-risk infants range from 10% to 87%. Early Moves is a population-based prospective cohort study of the predictive utility of GMA for developmental outcomes. The aim of this sub-study is to establish the rates of age-adequate movement repertoire in the Early Moves cohort.

Patients and Methods: Movement repertoire was assessed using 3-minute videos on 754 infants from the Early Moves cohort (mean gestation 38.8weeks [27.9-41.7weeks], mean birthweight 3334g [1580-4595g], 54% male). Videos were collected at 12-13 weeks post-term (n =459), 14-15weeks post-term (n=220) or 16+weeks post-term (n=75).

Results: Across all ages, >88% of infants exhibited at least 4 normal observed movement patterns. Normal foot-to-foot contact, obligatory from 12-13 weeks, was observed in 16% of infants in this age group. At 14-15weeks, when normal hand-to-hand contact is first obligatory, it was observed in 35% of infants. Normal leg lift, obligatory from 16+weeks, was observed in 44%, 56% and 64% of infants at 12-13weeks, 14-15weeks and 16+weeks respectively.

Conclusion: This is the first study to report rates of age adequate movement repertoire across the different age groups in a large population-based sample. Further research is required to understand how this relates to developmental outcomes.

Relevance for users and families:

Results support that MOS-R should not be used in isolation to assess infant development

Digital Teddy: a tool to assess children´s selective attention

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Introduction: Efficient selective attention is essential in daily life and plays an important role in childhood as it facilitates the development of movement or cognition. Among the tools assessing this type of attention, cancellation tests have been shown to have greater validity in preschool children. However, they are difficult tests to implement, because they depend on motor skills (usually using pencil and paper), and they have little studied psychometric properties. Teddy Bear Cancellation Test (TBCT) consists of the "cancellation" of 15 targets on a paper with 60 distractors. In this project, we have developed a digital version of TBCT (DT) to facilitate its administration. This study aims to determine the validity and usability of DT.

Patients and Methods: Eight typically developed children aged between 2 and 8 performed paper and tablet TBCT in a randomized single test session. Variables were number and location of omissions and location of the three first targets. The DT also registered pointing accuracy and global time. **Results**: Preliminary data showed that the number of omissions were similar in both original and digital TBC tests. Besides, DT registered more precisely data than the original (accuracy, time, etc.) and could be configured differently according to age or level of attention. Data also revealed very good administrators' satisfaction. Sample size is being expanded in number and medical conditions with risk of having attention deficits.

Conclusion: DT is suitable to reproduce TBCT because of it is easy to use, guarantees adequate data registration and allows to record extra variables.

Relevance for users and families:

DT might be useful in everyday clinical practice as it requires little time, few human and material resources and domestic and affordable technology, showing similar Results as the original test. Likewise, as it is an easy and quick tool to use, it can be implemented as a tool in educational or health centers, to help early detection of attention problems in children.

Which early motor assessment best explains motor performance of extremely preterm infants at two years: the ASQ-3, AIMS or NSMDA?

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Introduction: Increased survival of extremely preterm (EPT) infants necessitates population-based screening to identify children at-risk of later motor difficulties who need early intervention. This study aimed to determine whether 2-year-old motor performance of EPT infants was best explained by parent-reported questionnaire or clinical motor assessments at key timepoints in infancy.

Patients and Methods: Participants were all EPT infants from a prospective follow-up cohort (2015-2018, n=191, 60.2% male, mean[SD] gestational age 26.83[1.83]weeks). Parents completed the Ages and Stages Questionnaire (ASQ-3; 4-, 8- and 12-months). Infants were assessed on the Alberta Infant Motor Scale (AIMS; 4-, 8-, 12-months), Neuro-Sensory Motor Developmental Assessment (NSMDA; 4-, 8-, 12-months, 2-years) and Bayley Scale of Infant and Toddler Development (Bayley-III; 2-years). Friedman's tests were used to assess stability of infant performance on each measure. Multiple linear regressions were used to identify infant assessments best explaining 2-year-old performance.

Results: Motor performance was substantially (AIMS 76.95% agreement) to highly (ASQ-3 88.68%, NSMDA 82.03%) stable throughout infancy. Using single time-point analysis, 2-year NSMDA performance was best explained by 12-month AIMS and NSMDA scores and socioeconomic status; 2-year Bayley-III motor score was best explained by 4-month NSMDA scores, gestational age, size for gestational age and socioeconomic status. Using multiple time-point analysis, 2-year Bayley-III and NSMDA scores were best explained by 8-month NSMDA and 12-month AIMS scores.

Conclusions: Motor performance of EPT infants is substantially-highly stable during infancy. Two-year-old motor performance is better explained by early NSMDA and/or AIMS motor performance scores than by ASQ-3 questionnaire scores.

Relevance for users and families:

These Results emphasise the value of infant follow-up programs to monitor motor development of preterm-born children. Data provides clarity that physical motor assessment is superior to parent questionnaire in identifying infants with motor difficulties that may persist into later childhood. Follow-up should be provided at regular intervals, with 4-, 8- and 12-months showing significant relationships with 2-year-old performance. In-person and telehealth options should be investigated for equitable service access for geographically distributed children and families.

Implementation of Guidelines of Early Detection in Infants at High-Risk of Cerebral Palsy. A Spanish Two-Center Study.

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Introduction. International clinical practice guidelines for early detection of cerebral palsy (CP) were published in 2017. Since then, international implementation efforts have been made to improve high-risk infant follow-up programs. Our study aims to implement the most predictive tools for detecting the risk of CP in two Spanish settings.

Patients and Methods. A prospective observational case series study of infants with high-risk indicators identifiable in the newborn period was conducted. Infants were attended the Hospital Universitario Insular Materno Infantil (Las Palmas de Gran Canaria, Spain) and the Hospital Universitario de Toledo (Toledo, Spain). The primary outcomes were "high-risk for cerebral palsy" designation based on the Prechtl's General Movements Assessment (GMA) with cramped-synchronized or absent fidgety patterns, the Hammersmith Infant Neurological Examination (HINE) with scores below predicted threshold, and neuroimaging with specific patterns predictive of CP. In addition, age at CP diagnosis and age at referral for early intervention services were also studied.

Results. Since May 2022, 31 infants have participated in the study. Neuroimaging (serial cranial ultrasounds and/or Magnetic Resonance Imaging), GMA, and HINE assessment at 3, 6, 9, and 12 months have been collected. Results in terms of age at CP diagnosis and referral to early intervention services will be compared with previous quarterly records prior to implementation of the guidelines (same calendar months in the previous year).

Conclusion. Preliminary Results from this study suggest that "high-risk" for CP, or CP, can be accurately detected through an evidence-based follow-up program. Its clinical implementation also promotes early referral to intervention.

Relevance for users and families:

Perceived delays in receiving a diagnosis of CP have been previously reported in the literature, related to potentially worse outcomes in infants' and children functioning and family system mental health — parental depression and increased stress. Implementation of international guidelines for early detection could support early diagnosis and specific intervention for CP, complication prevention, and parental support.

The Pediatric version of the Eating Assessment Tool-10: Can this tool be used to discriminate aspiration in cerebral palsy?

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Introduction: Children with cerebral palsy (CP) frequently experience deglutition disorders, of which approximately 50% had airway aspiration. Therefore, it is important to detect aspiration in clinical settings in early period to prevent aspiration related complications including dehydration, malnutrition, and respiratory problems. The Pediatric version of the Eating Assessment Tool-10 (PEDI-EAT-10) was reported to be used as a discriminative tool to identify aspiration risk in children with neurological impairments. The aim of the present study was to evaluate the ability of the PEDI-EAT-10 to define aspiration in CP.

Patients and Methods: One hundred-fifty children were included. A Modified Barium Swallowing Study was performed to determine penetration and aspiration severity, which was scored by the penetration and aspiration scale (PAS). The PEDI-EAT-10 was used for dysphagia symptom severity.

Results: The mean age of children was 53.00±36.10 months (min=18, max=131), of which 53.4% were female. There were strong positive correlations between PEDI-EAT-10 and PAS score from liquid ($p<0.001$, $r=0.71$) and pudding swallowings ($p<0.001$, $r=0.70$). The sensitivity of a PEDI-EAT-10 score greater than 12 in predicting liquid aspiration was 91% and the specificity was 57%, and sensitivity of a PEDI-EAT-10 score greater than 12 in predicting pudding aspiration was 96% and the specificity was 51%.

Conclusion: The PEDI-EAT-10 is an easy-to-used dysphagia-screening tool with good discriminant ability of airway aspiration in children with CP.

Relevance for users and families:

As a quick, easy-to-use and sensitive screening tool, PEDI-EAT-10 could be used to identify high-risk children with CP for further instrumental swallowing evaluation.

Psychometric properties of functional postural control tests in children: a systematic review

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Introduction: Postural control deficits are one of the most common impairments in pediatric physiotherapeutic practice. Adequate evaluation of these deficits is imperative for identification, treatment planning and treatment efficacy. Although a gold standard is still lacking, research into the psychometric properties of functional pediatric postural control tests has increased significantly over the last decade. The aim of this systematic review was to facilitate the selection of an appropriate pediatric functional postural control test in research and clinical practice.

Methods: Following the PRISMA guidelines, PubMed, WoS and Scopus were systematically searched (last updated: June 2022; PROSPERO: CRD42021246995). Studies were selected using the PICOs-method (pediatric populations (P), functional postural control tests (I), psychometric properties (O). Risk of bias was rated with the COSMIN checklist and level of evidence determined using GRADE. Per test, the postural control systems were mapped, and the psychometric properties extracted.

Results: Seventy studies were included investigating 26 different postural control tests. Most children were healthy or had cerebral palsy. Overall, the evidence for all measurement properties was (very) low. Most tests (95%) showed good reliability (ICC>0.70), but inconsistent validity Results. Structural validity, internal consistency and responsiveness were only available for three tests. The Kids-BESTest and FAB exclusively cover all postural control systems.

Conclusion: Currently, two functional tests comprehend the entire postural control construct. Although reliability is overall good, validity Results depend upon task, age and pathology. Future research should focus on test batteries, especially further exploring structural validity and responsiveness in various populations with methodologically strong study designs.

Relevance for users and families:

With this systematic review clinicians are able to select an appropriate postural control test. The children and parents benefit from an adequate postural control test, because it aids in the identification of true postural control deficits which facilitates specific individualized treatment goal setting, saving time and providing targeted treatment related to their request for help.

Correlating asymmetries in high-risk infants identified using General Movement Assessment and Hammersmith Infant Neurological Examination with later outcomes

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Introduction: Prechtl General Movement Assessment (GMA) and Hammersmith Infant Neurological Examination (HINE) support identification of neuromotor deficits. Asymmetries in 3-month high-risk infants were compared to later function/asymmetries with HINE and Bayley Scales of Infant and Toddler Development, (Bayley-4) at 6-12 months.

Setting: Lurie Children's NICU Clinic

Patients/Methods: 241 infants [median GA 32 (IQR:28-38) weeks] had HINE and GMA Motor Optimality Score (MOS) at 3-months corrected age [median PMA 53 (IQR: 53-54) weeks]. At 6-10 months corrected age [median 7 (IQR:6-9) months], 151 infants had Bayley-4 and 112 infants had repeat HINEs. GMA and HINE asymmetries at 3-months were correlated to later HINE and Bayley-4. Cerebral palsy (CP) diagnoses collected.

Results: At 3 months, 73 infants (30.3%) had >1 MOS asymmetry, 103 (42.7%) had >1 HINE asymmetry. HINE and MOS asymmetries were correlated ($p<0.027$).

At 6-10 month Bayley-4, those with >1 MOS asymmetry at 3-months had significantly lower motor composite scores (88.8+2.5) than those with <1 asymmetry (99.2+1.2; $p<0.001$) and higher rates of motor composite scores <85 (23.3% vs. 7.7%, $p<0.001$). HINE asymmetry >1 at 3-months correlated with lower composite language ($p=0.037$) and motor ($p=0.034$) Bayley-4 scores.

112 infants with 6-10 month HINEs, 50 (44.6%) decreased, 27 (24.1%) unchanged and 35 (31.3%) increased. Of the 62 infants with increased/unchanged asymmetries, 18 (29%) were diagnosed with CP, no child with decreased asymmetries were diagnosed with CP to date ($p<0.001$).

Conclusion: GMA-MOS and HINE provide early insight into cognitive/motor outcomes. Repeat HINE testing to monitor asymmetry persistence may assist with early CP diagnosis.

Relevance for users and families:

Understanding the significance of early detailed screenings with GMA and HINE can encourage providers and families to look further in the setting of clinically identified asymmetries. Fostering early awareness of asymmetries can empower clinicians and caregivers to monitor children for the potential need for interventions. This also begins the discussion between providers and caregivers to support enriched active movement opportunities with a focus on postural control including midline orientation for better outcomes.

Manual dexterity abilities and dual-tasking in children with and without Developmental Coordination Disorder (DCD)

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Introduction: Poor manual skills in children with Developmental Coordination Disorder (DCD) may be due to difficulties in the automatization phase of the motor learning process. A way to test this hypothesis is by using a dual-task paradigm. We aim to (1) investigate manual dexterity abilities using increased levels of difficulty and (2) dual-tasking using an experimental protocol of the Tyneside Pegboard Test (TPT).

Patients and Methods: TPT's experimental conditions (unimanual, bimanual and dual-task) were administered. Dual-task paradigm consisted of a primary unimanual task (displacement of small pegs from left to right side) and a cognitive task (auditory-choice reaction task). Sixteen children with DCD (mean age 7y9m, SD 1y2m, 4F:12M, range 6-10y) and high percentage of comorbidity were included and 16 age-matched typically developing (TD) children (mean age 7y9m, SD 1y4m, 7F: 9M, range 6-10y). All parents filled out the eConners questionnaire to report attentional difficulties. Repeated measures ANOVAs were used to compare tasks between groups. Pearson correlation coefficients were calculated between dual-task performance and ADHD index.

Results: Children with DCD performed significantly worse than TD children in all unimanual ($p=.03$, effect size (d) =.16) and bimanual ($p<.001$, $d=.66$) conditions. Children with DCD showed poorer dual-task performance, but only with the -less experienced- non-dominant hand ($p=.03$, $d=.17$). ADHD index did not correlate significantly with dual-task performance of the two hands in the two groups.

Conclusions: Children with DCD present slowness and, as suggested by the multiple resource of attention model, difficulties in the automatization process of a motor task.

Relevance for users and families:

New insights on manual dexterity abilities and their motor learning in children with DCD useful for detecting novel rehabilitative approches in activities of daily life

Contribution of different impairments to restricted knee flexion during gait in individuals with cerebral palsy

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Introduction: The coexistence of overlapping impairments modulates the knee pattern in the swing phase of walking in children with cerebral palsy (CP). The impact and contribution of each impairment to the reduction of knee range-of-motion is unknown. The aim of the study was to establish the gradation of the impact of individual coexisting impairments on the knee flexion range-of-motion.

Patients and Methods: Passive range-of-motion, selective motor control, strength, and spasticity from 132 patients (Male = 76, Female = 56, age: 11 ± 4 years) with spastic CP were tested with clinical tools. Knee flexion range-of-motion at terminal stance, pre-swing, and initial swing phases were assessed by gait analysis.

Results: Hypertonia (β = −5.75) and weakness (β = 2.76) of knee extensors were associated with lower range of knee flexion (R^2 = 0.0801, F = 11.0963, p < 0.0001). The predictive factors (R^2 = 0.0744, F = 7.2135, p < 0.0001) were strength (β = 4.04) and spasticity (β = −2.74) of knee extensors and strength of hip flexors (β = −2.01); in swing those were knee extensors hypertonia (β = −2.55) and passive range of flexion (β = 0.16) (R^2 = 0.0398, F = 3.4010, p = 0.01).

Conclusion: Hypertonia of knee extensors has the strongest impact on knee flexion range-of-motion; secondary is the strength of knee extensors. The knee extensors strength with knee extensors hypertonia and strength of hip flexors contributes in stance. Knee extensors hypertonia with passive knee flexion range-of-motion contributes in swing.

Relevance for users and families:

Among all the coexistent impairments in patients with CP the strongest impact on knee gait pattern has Rectus Femoris spasticity

Neuroanatomical and clinical factors contributing to speech profile in verbal children with cerebral palsy

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Introduction. Cerebral palsy (CP) is a chronic motor disorder often associated with communication impairment. In particular, motor speech disorders such as dysarthria can negatively impact adaptive behaviour and quality of life. Knowledge on factors associated with motor speech impairment in CP is still limited, despite the potential benefits in identifying targets and predicting outcomes in intervention studies. We aim at assessing factors associated with the motor speech profile in verbal children with CP, including neuroanatomical characteristics of cerebral lesion on brain MRI, gross motor function, cognition and language characteristics.

Patients and Methods. Thirty-four verbal children with CP aged 4 to 10 years were included in this cross-sectional study. Motor speech skills were assessed through the Verbal Motor Production Assessment for Children (VMPAC). Each of the five subscales' scores were entered in a separate regression model. Brain lesion timing, site, severity and laterality indices, Gross Motor Function Classification System (GMFCS), language comprehension and cognitive measures were analyzed.

Results. All the five generated models reached statistical significance ($p < 0.05$, range: 0,02 to <0.0001), with explained variability ranging from 47% to 64%. Neuroanatomical brain lesion characteristics made a significant unique contribution to the prediction of almost all the subscales of the speech motor assessment.

Conclusion. Speech motor characteristics in CP may be predicted by neuroanatomical lesion and CP clinical characteristics. Targeted intervention strategies are emerging, which requires a better understanding of predictors of speech motor function and of potential intervention targets, given the potential strong consequences on quality of life and adaptive behaviour.

Relevance for users and families:

This study provides insights into the understanding of factors associated with speech profile in CP. Speech motor abilities are neither extensively explored nor considered as systematic targets for intervention. A deeper knowledge may impact on establishing targeted intervention and to provide factors potentially associated with response to specific rehabilitation programs. A rationale approach may substantially impact on adaptive behavior and quality of life of children and families.

Severity of Cerebral Palsy According to the Impairment Index

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Introduction: The aim was to describe the impact of associated impairments in accordence with impariment index children with cerebral palsy (CP) and its subtypes.

Patients and Methods: 410 children with CP retrospectively included. Low-impairment (LI) defined being GMFCS I–II, IQ>70, no visual, hearing impairment, epilepsy. High-impairment (HI) defined being GMFCS IV–V and/or severe intellectual impairment (IQ<50) with/without severe visual, hearing impairment, active epilepsy. Moderate-impairment (MI) is, GMFCS I–II, IQ>70, with one or more impairments: severe visual, hearing impairment, active epilepsy, or GMFCS I–II with an IQ>50 and <70, with/without one/more of severe visual, hearing impairment, and/or active epilepsy OR GMFCS III, with an IQ>50 with or without one/or more of the following impairments: severe visual, hearing impairment, and active epilepsy. Distribution of impairment index among GMFCS levels and CP subtypes investigated.

Results: The distribution among GMFCS levels LI: GMFCS-I: 75(19%), GMFCS-II: 54 (13.5%); MI GMFCS-I: 24 (6%), GMFCS-II: 55 (14%), GMFCS-III: 73 (18%), HI GMFM-IV: 64 (16%), GMFM-V: 58 (14.5%). Among CP subtypes; LI, hemiplegia: 64 (16%), diplegia: 39 (10%), diskinesia: 6 (1.25), ataxia: 9 (2%); MI hemiplegia: 39 (10%), diplegia: 76 (19%), quadriplegia: 12 (3%), diskinesia: 9 (2%), ataxia: 8 (2%), unclassified: 5 (1.1%); HI, diplegia: 10 (2.2%), 59 quadriplegia (15%), diskinesia: 37 (9%), ataxia: 2 (0.5%), unclassified: 12 (3%).

Conclusion: 30% of children with CP had a LI that means were able to walk unaided and had a normal/near-normal IQ. Majority of bilateral spastic and/or diskinetic involmemet had MI and HI.

Relevance for users and families:

It is important understand the severity of impairment to develop specific rehabilitation approaches ans social policies.

Implications of the PREMTiME study Results on developmental surveillance for very preterm and very low birth weight infants.

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Introduction: The PREMTiME study aimed to identify early clinical biomarkers from birth to 16 weeks corrected age (CA) to predict typical outcome and developmental delay at 24 months CA. Findings indicate only the General Movement Assessment (GMA) had sufficient predictive validity to identify both conditions: typical outcome and developmental delay (motor or cognitive).

Patients and Methods: A prospective cohort of infants on the Sunshine Coast, Australia, were assessed using the Premie-Neuro Examination, the GMA, the Alberta Infant Motor Scale, and the Infant Sensory Profile 2. At 24 months CA, delay was identified using the Bayley Scales of Infant and Toddler Development, Third Edition and Neurosensory Motor Developmental Assessment.

Results: Of 104 infants recruited; 79 completed outcome assessments (43 females, 36 males; gestational age 30 weeks [SD 1 week 6 days], mean birthweight 1346 g [SD 323]). The incidence of developmental delay (motor or cognitive) was n=5, 6.3%. GMA trajectories with abnormal writhing at 4 to 5 weeks CA and suboptimal quality of fidgety movement at 16 weeks CA (intermittent, sporadic, abnormal, absent) were strongly predictive of developmental delay, superior to all other clinical tools and perinatal/demographic variables investigated ($p = 0.01$, Akaike information criterion method 18.79 [score corrected for small sample size], accounting for 93% of the cumulative weight).

Conclusion: Targeted use of the GMA trajectory from birth to 16 weeks CA can help clinicians prioritise follow up services, facilitate referral to early intervention and provide parents with an estimate of their child's risk for developmental delay (motor or cognitive).

Relevance for users and families:

The enhanced potential for early detection of developmental delay supports international guidelines advocating early intervention for optimisation of participation and quality of life. Incorporating these findings within service delivery has the potential to allow customisation of developmental follow up programs, reduce issues of attrition, decrease over servicing and facilitate targeted essential early intervention. Most importantly, clinicians may now engage in earlier conversations with families looking for answers about the impact of their child's preterm birth.

Investigation of automatization abilities and dual-tasking in children with and without Cerebral Palsy: a pilot study

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Introduction: Motor automatization is an important process in motor learning. In children with Cerebral Palsy (CP), difficulties in learning new action sequences are often reported in addition to motor impairment. Dual-task paradigm is usually used in CP to investigate gross-motor skills rather than manual dexterity skills.

We aim to investigate the ability of automatization by using an experimental dual-task condition of the Tyneside Pegboard Test (TPT).

Patients and Methods: 8 children with CP (mean age: 7,57y; SD: 1,25), both 4 UCP and 4 DCP and 16 age-matched typically developing children (mean age: 7,98y; SD:1,25) were included. The experimental protocol involves a task and a dual-task (motor/acoustic) with small pegs. All tests are video recorded, performed with affected and non-affected hand. Execution time is measured. For the statistical analysis, repeated measures ANOVAs were used to compare different conditions of the TPT between groups.

Results: We found a significant difference in two groups in speed of execution between single task and dual-task (p=.009) with the non-affected hand.

Conclusions: Children with CP are slower with the non-affected hand. This finding is online with the hypothesis that they can face an automatization deficit that impairs their manual performance beside the motor difficulties.

Relevance for users and families:

Despite the small number of children with CP, the relevance of this pilot study is the possibility to have a tool to investigate the planning and automation difficulties that often affect the children with CP and that are usually difficult to assess.

Investigation of The Suitability of Quality of Upper Extremity Skills Test for Tele-Assessment in Children with Cerebral Palsy: A Pilot Study

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Introduction: Tele-assessment is the remote assessment of the patient in non-clinical settings. It is essential for the tele-rehabilitation. The aim was to investigate the suitability of the Quality of Upper Extremity Skills Test (QUEST) for tele-assessment in children with spastic hemiplegic cerebral palsy (CP).

Patients and Methods: A total of 15 children with CP, aged 5-12 years, classified as Manual Ability Classification System (MACS) level 1-2 were included in the study. The upper extremity skills were evaluated two times: face-to-face in the clinic, and tele-assessment via video-conferencing. Both assessments were scored separately and the intra-class correlation coefficient (ICC) was examined to determine the agreement between both assessments.

Results: The mean age of children was 9.27±4.33 years. five children were on MACS level 1 and rest was level 2. The ICC for the total score of the QUEST was 0.858 (95%CI:0.056-0.967, p<0.001). ICC values were 0.845 (95%CI:0.516-0.952, p<0.001), 0.921 (95%CI:0.703-0.977, p<0.001), 0.677 (95%CI:-0.222-0.912, p=0.002) and 0.676 (95%CI:-0.161-0.907, p=0.004) for the A (dissociated movements), B (grasp), C (weight bearing) and D (protective extension) domains of QUEST, respectively.

Conclusion: The QUEST is reliable tool to evaluate upper extremity skills in children with CP. However, C and D domains had low reliability.The possible reason for this is that the patients change positions in these sections and the camera angle is insufficient. The prevalence of such studies may allow reliable evaluation of patients remotely without coming to the clinical setting.

Relevance for users and families:

If the obstacle of "evaluating the patient in the clinical setting and determining the therapy program" in front of tele-rehabilitation can be removed by showing the suitability of tools for remote-assessments, we can talk about te-rehabilitation in the real sense.

Theresa Sukal-Moulton, Vanessa Barbosa, Barbara Sargent, Colleen Peyton

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Introduction: Individuals with spastic CP have difficulties with independent joint control (IJC; i.e. ability to move one joint at a time), but no clinical tool exists to measure IJC in infancy. Our aim was to test the reliability of a new systematic approach that measures IJC in infancy called “baby Observational Selective Control AppRaisal” (babyOSCAR).

Patients and Methods: Two rater pairs quantified independent joint movement behaviors of a set of 30 infants at 3 months corrected age using 1 minute video clips during infant spontaneous movement. Among these infants, 15 had typical development (TD) and 15 had a confirmed diagnosis of spastic CP at age 2 or older. In a subset of 12 infants, 2 different 1-minute clips were scored. A score of 1 was given each time an instance of independent joint motion was observed in the upper extremities (UE) and lower extremities (LE). The total score could range from 0 to 32.

Results: Interrater reliability was excellent for total score and LE (ICCtotal=0.876, ICCLE=0.876, $p<0.001$) and good for UE (ICC=0.545, p=0.019). Test-retest reliability was excellent for total and LE (ICCtotal=0.842, p=0.002 and ICCLE=0.993, $p<0.001$) and good for UE (ICC=0.570, p=0.081).

Conclusion: BabyOSCAR can be reliably used among raters and between testing times. Longer clips may be warranted when scoring the upper extremities with the BabyOSCAR.

Relevance for users and families:

The BabyOSCAR is a reliable tool that may be able to 1) improve prognosis at an earlier age and 2) target treatments towards the joints of the body that have less observed selective control in infancy.

Associations of parent-reported pragmatic language and communication and modified ADOS-2 in children with visual impairment (VI).

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Introduction: Children with congenital profound or severe VI are at high risk of ASD and social-communication difficulties (Do et al 2017). This study investigated pragmatic language abilities in children with severe-profound VI using the Children's Communication Checklist (CCC-2) parent questionnaire which has good sensitivity/specificity in detecting children with autistic symptoms and pragmatic language impairment (Bishop, 2006). The aims were to assess the recently validated and modified ADOS-2 for children with VI (Dale et al, submitted) against the CCC-2.

Patients and Methods: Seventy children with 'potentially simple' congenital disorders of the anterior visual system and severe-profound VI participated in the study (Mean measurable logMAR=.98, range=.23-2.5); (Mean age=67.35 months, SD=.56). Parents filled out the CCC-2 and children participated in a modified version of ADOS-2® which was validated with a new algorithm (Dale et al, submitted), and classified into High-Risk and Low-Risk of ASD.

Results: Subscales of the CCC-2 were categorised into three scales, General Structural Scale, General Pragmatic Scale, and Social Communication/Interests Scale. Spearman correlations revealed no significant differences between vision severity and the three scales. Mann-Whitney U tests revealed that children in the High-Risk group scored lower on the Social Communication/Interests Scale ($p<.05$), but not the General Structural Scale ($p>.05$) or General Pragmatic Scale ($p>.05$), compared to the Low-Risk group.

Conclusion: Low scores on the parent-rated CCC-2 Social Communication/Interests scale raise concern regarding children with VI of this age. Referral to services for diagnostic consideration with VI-modified ADOS-2 (in preparation for future dissemination) and other assessment Methods may be indicated.

Relevance for users and families:

This work is relevant to parents and family members of children with visual impairment. ASD is very prevalent in visually impaired children and early identification of it via the Methods mentioned here is of great importance. Tools such as the ones mentioned in the abstract are being validated for the visually impaired for the first time.

Chromosomal Microarray and Next Generation Sequencing test in Patients with unexplained intellectual disability

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Introduction: intellectual disability (ID) is neurodevelopmental disorder manifested by impaired cognitive function and delayed adaptive behaviors. We have investigated the diagnostic yield of genetic tests in children with unexplained ID using chromosomal microarray (CMA) and targeted NGS, and analyzed the characteristics of the Results.

Method: The children who visited the pediatric rehabilitation department and underwent genetic testing (CMA and targeted NGS) for unexplained ID were included. The children who were diagnosed in advance (e.g. karyotyping, Prader Willi syndrome, Fragile X syndrome, etc.) were excluded. The characteristics of the child were checked for the combined gross motor delay, epilepsy, facial dysmorphism, micro/macrocephaly, and congenital structural anomaly. The pathogenicity of variants was classified as causal variant-having sufficient evidence, or possible causal variant-missing some evidence. These categories were defined based on the ACMG guideline, considering phenotypes, genotypes, previous literature reports, pedigrees, and other tests.

Results: A total of 119 patients were included. The causal variants were identified in 29 (24.4%) patients (CMA 12 and NGS 16). In addition, possible causal variants were found in 13 (10.9%) cases (CMA 2 and NGS 11). Children diagnosed with CMA or NGS were significantly more likely to have gross motor delay (Odds ratio (OR) 11.2, p <.001), facial dysmorphism (OR 8.86, p <.001), or structural anomaly (OR 4.24, p =.002).

Conclusion: The diagnostic yield of karyotyping, CMA, and NGS in children with unexplained ID was about 24-35%. The diagnosis rate was significantly higher when gross motor delay, facial dysmorphism, or structural anomaly were combined.

Relevance for users and families:

It contains information necessary for experts who treat children with unexplained intellectual disabilities or diagnose underlying genetics.

Concurrent and predictive validity of the Alberta Infant Motor Scale and the Peabody Developmental Motor Scale-2, administered to infants born very preterm in Norway

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Introduction: The correlation between the Alberta Infant Motor Scale (AIMS) and the Peabody Developmental Motor Scale-2 (PDMS-2) has not previously been assessed in Norwegian infants. Our purpose was to investigate the concurrent validity of the AIMS and the PDMS-2 in a group of infants born very preterm in Norway, and to investigate the predictive validity of the two tests for atypical motor function at 24 months post term age (PTA).

Materials and Methods: The infants (n=139) had participated in a randomized controlled trial of early physiotherapy intervention. As part of this study, they had been assessed by the AIMS and the PDMS-2 at 6- and 12-months PTA, and by the PDMS-2 at 24 months PTA.

Results: The correlation between the AIMS and the PDMS-2 (total motor and gross motor standard scores), at 6 months, was r=0.44 and r=0.50, and at 12 months r=0.56 and r=0.67 respectively. The predictive validity for atypical motor function at 24 months, assessed using the area under the curve (AUC) at 6- and at 12- months, was for the AIMS 0.87 (95% CI:0.74 – 0.99) and 0.86 (95% CI:0.66 – 1.00) respectively, and for the PDMS-2 gross motor quotient 0.72 (95% CI 0.57 – 0.86) and 0.83 (95% CI:0.58 – 1.00) respectively.

Conclusion: The correlation between the AIMS and the PDMS-2, at 6- and 12- months, in a group of Norwegian infants born preterm, was only fair to moderate. The AIMS as compared to PDMS-2 was a better predictor of atypical motor development at 24 months.

Relevance for users and families:

Since the AIMS is a shorter and less time-consuming test it might be a preferable tool when assessing motor function at 6- and 12-months PTA, in infants born preterm. This is both an advantage for the babies and their parents.

Paediatric ASPECTS identifies patients requiring early clinical assessment in an Early Intervention Clinic

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Introduction: To investigate the correlation between pedASPECTS and the recommended clinical examinations of General Movements Assessment (GMA) and Hammersmith Infant Neurological Examination (HINE) as well as diagnosis of cerebral palsy (CP) and clinical outcomes in infants who have suffered a neonatal arterial ischaemic stroke.

Methods: A retrospective study of patients seen between July 2018 and June 2021 in the Early Intervention Clinic (EIC) at Perth Children's Hospital (Western Australia's sole tertiary paediatric hospital). The cohort was identified by an electronic database search, MRI scans were retrospectively scored by a paediatric neuroradiologist and clinical data was extracted from medical records. A correlation test, exploratory data analysis and visual inspections were used to investigate the relationship between pedASPECTS and HINE scores, CP diagnosis, Fidgety GMA result, and clinical outcomes.

Results: Preliminary data from the initial search identified 22 patients and 17 met inclusion criteria. Median age at first assessment was 2.8months corrected, HINE score was available for 94% and fidgety GMA for 82%. Median pedASPECTS was 8. 9 patients were diagnosed with CP and 12 required long-term follow up. A correlation test resulted in a significant, moderate negative correlation of -0.52 ($p<0.05$), where increased pedASPECT score indicates a decrease in HINE score.

Conclusions: This study has shown pedASPECTS negatively correlates with HINE score and has identified relationships with fidgety GMA, CP diagnosis and requirement for long term follow up. PedASPECTS can be valuable in identifying neonates at higher risk of abnormal neurological development and in need of early assessment and intervention.

Relevance for users and families:

Including the pedASPECT score contemporaneously in the standard reporting protocol of neonatal arterial ischaemic stroke on MRI provides an opportunity to improve information delivery to both parents/ carers and medical professionals during the initial neonatal inpatient stay. This can encourage timely referral to early intervention services to implement both early assessment and intervention.

Sensory profiles of school aged children who underwent hypothermia treatment for neonatal hypoxic ischaemic encephalopathy

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Introduction: Hypothermia treatment for hypoxic ischaemic encephalopathy (HIE) has resulted in reductions of neurodevelopmental disability; however, there is a need for long-term assessment of cognitive and behavioural functioning including that of sensory processing. Sensory processing disorders have been recognised in children with cerebral palsy (CP), however, have not been investigated in children with HIE without CP.

Patients and Methods: Children aged 6-8 years with a history of neonatal HIE (N=52) and without CP, were compared to an age-matched neuro-typical control group (N=41) on the Wechsler Intelligence Scale (WISC-V) and the Sensory Profile 2 Child and School Companion.

Results: HIE children had reduced WISC scores compared to controls (M=92.53;SD=17.6 vs. M=110.33;SD=10.14, $t(82) = 5.569$, $p < .001$). For sensory processing scales, HIE children scored higher in parent and teacher reports than controls for seeking (Md=28;10 vs. Md=23;8), avoiding (Md=34.5;13 vs. Md=31;12), sensitivity (Md=30;15 vs. Md=24;11.5), auditory processing (Md =17.5;9.5 vs. Md =12;7) and movement processing (Md=12;10 vs. Md=8;8). The teacher reports had also higher scores for registration (Md=15 vs. Md=13), external support, tolerance, and learning availability (Md=15;14;10 vs. Md=13;12;9), all U's > 257.5, all p's <.05). After controlling for IQ, there were no significant effects of group on sensory profiles however, IQ was significantly related to sensory profile scores.

Conclusion: This study indicates that children with HIE have significantly more sensory processing difficulties than typically developing children and that those with lower general cognitive ability, may display more sensory issues. Further analysis will consider the impact of deficits on learning and behaviour.

Relevance for users and families:

This research supports in further understanding the long term outcomes of children who underwent hypothermia treatment for hypoxic ischaemic encephalopathy (HIE) at birth. In recognising the difficulties in sensory processing and general cognition in children with HIE; follow up protocols can therefore consider the need for intervention and support. Furthermore, this research also allows us to explore the impact on adaptive behaviour and school readiness.

Autosomal dominant intellectual development disorder with behavioral abnormalities and epilepsy

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We are presenting a 2,5-years old child born at term with a birth weight of 2800 g, with seizures starting at age 1-year with diffuse EEG changes and intellectual development disorder. The clinical diagnosis included West syndrome and later Lennox–Gastaut syndrome. The treatment included oral antiepileptic drugs which was revised several times due to refractory seizures (vigabatrin, vigabatrin and valproic acid, with an episode of clinical worsening on levetiracetam). Currently he is controlled on triple therapy with Developmental assessment was carried out using Griffiths developmental scales at 12, 18 and 24 months of age, showing an orderly development of gross and fine motor skills, with mild deviation in the development of cognitive, speech and social-emotional abilities (development sub-coefficient 64%). The early onset and treatment resistance prompted diagnostic genetic testing using epilepsy and developmental gene panel identified a NAA15 likely pathogenic splice site variant c.2302+1G>T (also known as R466X), confirming a genetically determined neurological condition – autosomal dominant intellectual development disorder 50, with behavioral abnormalities (OMIM 617787). NAA15 gene codes for the auxiliary subunit of the N-terminal acetyltransferase A complex and is involved in brain development. The family history was unremarkable and parents not available for testing. This case illustrates the power of genomic testing in establishing a diagnosis in neurodevelopmental conditions, particularly in treatment refractory epilepsy syndromes with early onset.

Relevance for users and families:

This case illustrates the power of genomic testing in establishing a diagnosis in neurodevelopmental conditions, particularly in treatment refractory epilepsy syndromes with early onset.

Agreement between remote and in person assessment using functional tests in children with cerebral palsy

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Introduction:Social distancing during pandemic accelerate the usage of remote physiotherapy due to the ability to overcome service access barriers and provide continued care. However, little is known about the validity and reliability of functional assessment in children with cerebral palsy (CP) using synchronous forms of telehealth.

Patients and Methods:The purpose of this study was to investigate the agreement between remote assessment, using synchronous forms of telehealth and in person clinical evaluation using four functional tests, the tests used were five times sit to stand test(FTST), timed up and go(TUG), lateral step up test(LSU) and the pediatric balance scale(PBS). All tests are reliable for assessing balance and mobility in children with CP. A convenience sample of 11 children (7 boys and 4 girls) aged 6-11 years, with CP and GMFCS level I to II, was used. Each participant performed four functional tests in person in the physiotherapy clinic and via remote assessment using the VSee patform at home, with 2 days apart. All tests were examined by the same physiotherapist.

Results:Both tests completed with safety and successfully in both experimental conditions. The agreement of the Results between the two conditions was confirmed by Bland Altman analysis. Also correlations were excellent between TUG-TUG remote (ICC 0.932), LSU-LSU remote (ICC 0.967), PBS-PBS remote (ICC 0.997) and good between FTSTS-FTSTS remote (ICC 0.754).

Conclusion: Remote functional assessment for FTSTS TUG LSU and PBS is feasible, valid and reliable for independently mobilized children with CP.

Relevance for users and families:

Literature on the implementation and use of remote assessment in pediatric patients is limited. In a survey many therapists commented on the positive aspects that digital health provides when children are assessed and provided intervention in their physical environment. Telerehabilitation likely will not replace the in-person clinical care for all patient populations, but it should be considered as an important complementary or additional model of care.

Examination of the effect of selective motor control on activity and participation in children with cerebral palsy

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Introduction: The aim of this study was to investigate the effect of lower extremity selective motor control on activity and participation.

Patients and Methods: Children who were diagnosed with spastic cerebral palsy (CP), aged between 4-18 years, with no Botulinum Toxin administration in the last 6 months, with no ortopedic intervention within last year and who were able to follow the instructions given were included in the study. Lower limb selective motor control skills were assessed with the Selective Control Assessment of the Lower Extremity (SCALE), activity levels with Gross Motor Function Classification System (GMFCS). Pediatric Quality of Life Inventory (PedsQL) and Functional Independence Measure for Children (WeeFIM) were used to measure participation.

Results: The mean age of 52 children (25 males 27 females) who participated in the study was 9.8 4.4 years. There was a high correlation between the SCALE and GMFCS ($r=-0.786$, $p<0.001$), a high correlation between the SCALE and PedsQL ($r= 0.728$, $p<0.001$) and a moderate correlation between the SCALE and WeeFIM ($r= 0.554$, $p<0.001$).

Conclusion: Selective motor control ability affects activity and participation levels in children with spastic cerebral palsy. Impaired selective motor control may cause limitation in daily life, decreases participation and adversely affects health-related quality of life in children with cerebral palsy. Therefore, it is important to improve selective motor control ability in children with spastic cerebral palsy.

Relevance for users and families:

It will demostrate the importance of selective motor control skills to increase the activity and participation levels of children with CP. It may be beneficial to give importance to selective motor control in the treatment program in children with CP..

Effect of natural, full-spectrum cannabis extract for severe behavioral problems in children with autism – open label trial in 20 children

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Introduction: Autism spectrum disorder (ASD) is characterized by deficits in social interaction, communication, interests, repetitive and restrictive patterns of behavior and often in intellectual disabilities. Also, about 50% of such patients suffer from severe behavioral problems (SBP). The aim of our study is to evaluate effects full-spectrum cannabis extract - FSCE (CBD:THC 10:1) in a small scale pilot study of children with SBP.

Patients and Methods: We included in this open-label 6 weeks trial of FSCE 20 patients, aged 3-26 years (mean 10,6), 16 boys and 4 girls. There was one pair of twins and two brothers. Most common comorbidities were epilepsy, ADHD, genetic syndromes and cerebral palsy. Patients were prescribed preparation of FSCE, starting dose of 0,01mg/kg/day THC, increased up to maximum dose of 1 mg/kg/day THC. Before the start parents completed questionnaires: Clinical Global Impression Severity (CGI-S), The Childhood Autism Rating Scale (CARS) and Modified scale of behavior for children. To assess symptom change, after 6 weeks they will complete Clinical Global Impression Improvement (CGI-I) and Parental Satisfaction Survey (PASS). Adverse effects will be documented.

Results: The research is ongoing, we are expecting first Results in few weeks.

Conclusion: Our study is still ongoing however based on published research we are expecting improvement of behavioral problems in our small cohort of children. More research is needed to determine the efficacy and safety of medical cannabis treatment for SBP in pediatric population, which could be used in addition or even substituted for some antipsychotic drugs currently used for ASD.

Relevance for users and families:

With this research we are expecting improvement of behavioral problems in our small cohort of children. More research is needed to determine the efficacy and safety of medical cannabis treatment for SBP in pediatric population, which could be used in addition or even substituted for some antipsychotic drugs currently used for ASD.

Rehabilitation for the leg edema related with the disseminated BCG infection and lymphadenitis in an immunocompromised 26-months-old boy

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Introduction: Bacillus Calmette-Guerin (BCG) vaccine can have complications like lymphadenitis and rarely can cause disseminated BCG infection in immunocompromised patients. We present a case where BCG vaccination led to disseminated BCG infection and lymphadenitis.

Case-presentation: A 28-month-old boy was referred to clinic of pediatric rehabilitation due to right lower extremity edema. He was born at term without complications. He received BCG vaccination at age of 1-month. From age of 2-months, he underwent recurrent fever and urinary tract infections. There were skin rashes on hands, foot, neck, abdomen. He was admitted to department of pediatrics due to fever at age of 6-months. In lymphocyte subset, T-cell was 0% and NK cell was 0.5%. Gene study showed IL2RG mutation in him and mother, and he was diagnosed as X-linked recessive severe combined immunodeficiency (SCID)-inherited from mother. Granulomatous inflammation with positive acid-fast bacilli were found in skin and bone marrow biopsies. He received anti Tuberculous medications and peripheral blood stem cell transplantation from father. At age of 28 months, right leg started to swell. Lymphoscintigraphy was not performed due to patient's conditions, and CT angiography in legs showed no evidence of thrombosis. However, enlarged paraaortic lymph nodes were found below SMA os that compressing infrarenal IVC, which implies lymphadenitis. Complex decongestive therapy, bandages, stockings were prescribed. After 1-year of treatment, leg edema improved.

Conclusion: This case illustrates disseminated BCG infection and lymphadenitis. Infection should be considered as a possible cause for leg edema. Complex decongestive therapy including bandaging, stockings can be effective.

Relevance for users and families:

There's no relevance for users and families. The authors have no relevant financial or non-financial interests to disclose.

Surfer's myelopathy in a 7-year-old boy: A Case report

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Introduction: Surfer's myelopathy is a rare spinal cord injury which occurs after surfing. It is known to be associated with hyperextension of back. We present a case of a 7-year-old boy who developed surfer's myelopathy after surfing.

Case presentation: A previously healthy 7-year-old boy was admitted for both legs weakness. He surfed for an hour in a prone position with back hyperextended. After surfing, he felt a weakness in both legs, and could not walk. He also complained sensory impairment below L3 dermatome, and urinary retention for which a Foley catheter was inserted.

At the time of admission, motor power grade of both legs were less than grade 2 with no deep tendon reflex. Whole spine MRI revealed that hyperintense T2 weighted signal in central cord from T9 to conus medullaris without abnormal enhancement, indicating acute myelopathy. The cerebrospinal fluid (CSF) study revealed high pressure of more than 20mmHg. American Spinal Injury Association Impairment Scale (AIS) grade on admission was grade C and the neurological level of injury was T12. To improve neurologic findings, methylprednisolone pulse therapy was performed for 5 days. After therapy, sensory impairment showed some improvements, and motor power of both legs started to improve. When foley catheter was removed at HD #13, he could urinate by himself. He is on physical and occupational therapy and prescribed bilateral ankle-foot-orthosis.

Conclusion: This is one of the youngest cases of surfer's myelopathy. To prevent this disease, any prolonged, repetitive hyperextension of spine should be discouraged in children.

Relevance for users and families:

There's no relevance for users and families. The authors have no relevant financial or non-financial interests to disclose.

Feasibility of community-based exercise for non-ambulant adults with childhood onset disability

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Introduction: Community-based exercise reduces the risk of developing chronic diseases and provides a way to increase physical activity. However, non-ambulant adults with childhood onset disability (COD) have limited opportunities to exercise in their communities. This study explored the demand for, and practicalities of delivering, community-based exercise for non-ambulant adults with COD.

Patients and Methods: Ulster University's Research Ethics Committee granted ethical approval for this study. Non-ambulant adults with COD were recruited via social media and relevant organisations. Participants took part in weekly exercise sessions in a local gym for four consecutive weeks. Existing gym equipment was adapted to provide access in differing ways for a range of need, as a result of lived experience input at the planning stage. At the end of the first three sessions, participants completed a survey to inform the subsequent session. Participants completed a focus group discussion after the final exercise session. Quantitative data were analysed descriptively and qualitative focus group data were analysed thematically.

Results: Ten of the 22 adults who responded to the recruitment invitation were eligible to participate in the study. No participants withdrew from the study and 70% completed all four exercise sessions. Themes identified from focus group data were: (i) 'it's not an option' highlighting demand and benefits associated with community-based exercise, and (ii) 'we can do better' through problem-solving and incorporating key ingredients.

Conclusion: There is a need for community-based exercise for non-ambulant adults with COD. However, adequate resources, training and facilities are required to facilitate delivery in practice.

Relevance for users and families:

This research need was identified through collaborative discussions with a local voluntary sector organisation that highlighted adult wheelchair users have limited opportunities to participate in exercise in their community. The research was then co-designed with this organisation and people with lived experiences including an adult with non-ambulant cerebral palsy and their carers. A local community gym with an interest in improving access to gyms was identified as the most appropriate setting for this research.

Environmental variables- demographics, maternal, family and child factors- observed in children with ASD (autism spectrum disorder), as part of "genetics in autism" study in India

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Introduction:ASD is a complex heterogenous entity with high genetic susceptibility and environmental factors contributing to its etiology. We present here the data on environmental variables observed in children with ASD in India, as part of "genetics in autism" study.

DESIGN:101child-parent-trio with ASD (DSM-V criteria) were assessed. Detailed demographics, family & medical history was collected and genetic analysis was done. 30 cases (29.7%) on WES (whole-exome-sequencing) showed pathogenic/likely pathogenic variants.

Results: Mean father's-age was 32.5 and mother's 29.7 years. 76.23% children were 1st birth-order and 49.5% had siblings. Multiple pregnancy was seen in 7.9%. 23.7% mother's had miscarriage/s. 8.9% marriages were consanguineous, 29.7% non-consanguineous, 61.3% had endogamy. Family history of neurodevelopmental delays was present in 38.6%. 22% siblings and 62.5% twins had developmental delays. ASD was seen in 16% siblings, 50% twins and 12.8% overall in the family (1st/2nd degree relatives). For index child, h/o convulsion was present in 7.9% and head circumference below 3rd/above 97th centile was detected in 22.7%.

In WES positive children, 16.6% of marriages were consanguineous. 5.8% siblings had ASD, but none in the surviving twin/triplet. Head-circumference was abnormal in 40%, h/o convulsions (all from WES positive group) was present in 26.6%.

Conclusion: With an increasing incidence of ASD, it is important to study the genetic- epigenetics-environmental co-relation. Although it is a small data, convulsions, head-circumference abnormalities and consanguinity seem to be more prevalent in children with positive genetic profile. Factors like endogamy and family-history needs to be studied in detail for better understanding of genetic-environment correlation.

Relevance for users and families:

ASD is a complex disorder with both genetics and environmental factors playing a role in its etiology. Environmental variables, especially socio-demographic factors like parental age, consanguinity, and medical factors like antenatal care, maternal health are modifiable to some extent. The study highlights the importance of looking at genetic-environmental correlation in ASD, both for policy changes at government level and for proper counselling (genetic, medical, social) at parental & family level for preventive care.

Participation indicators in adolescents with cerebral palsy reassessed within the scope of the Portuguese surveillance program

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Introduction: Adolescence has a special uniqueness for persons with cerebral palsy (CP), involving a very wide range of specific challenges for health and participation. This work aims to describe participation indicators in adolescents with CP reassessed within the Portuguese surveillance program.

Patients and Methods: In a "best case scenario" approach, three of Portugal's regions were selected covering 35% of the 2001-2003 national birth cohort. In addition to the clinical, functional, and school inclusion indicators, new elements were asked for notifiers that included, participation in physical/sports activities or health/social support.

Results: Notifiers retrieve information from 217 of 289 potential participants. 170 (78%) were reassessed, 25 (12%) individuals died, and 22 (10%) individuals changed residence outside selected regions.

As expected, no significant differences were found for CP clinical type or functional classifications. 124 (73%) of the reassessed adolescents had some form of health professional regular intervention - physiotherapy (n=99,58%), occupational therapy (n=56,33%), or speech therapy (n= 41,24%).

Although not statistically significant, the proportion of adolescents not integrated into the regular education system was higher compared to those registered in childhood (22% vs. 18%). 75 (44%) of the reassessed adolescents attended different sports activities, like swimming (19%), boccia (10%), and horse riding (7%).

Conclusion: Educational opportunities seem to decrease in adolescence for people with CP in Portugal, which implies the study of alternatives that can contribute to the quality of life. Expanding opportunities to participate in other activities deserve special attention, namely those favoring lifelong health indicators, like sports or physical activity.

Relevance for users and families:

Illustrates the risks and opportunities of age transitions for people with cerebral palsy.

Developmental & medical conditions observed in family members of children with ASD (autism spectrum disorder) as part of "genetics in autism" study in India

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Introduction:ASD is a complex heterogeneous disorder with a prevalence as high as 1:44 on CDC's Autism & Developmental Disorders Monitoring (ADDM) network. Higher prevalence of autism and neurodevelopmental disorders is noticed in siblings of children with ASD. We present here a case-series of developmental and medical conditions observed in siblings/family members of children with ASD, as part of our "genetics in autism" study in India.

DESIGN:101 child-parent-trio's data with ASD (DSM-V criteria) was assessed for the genetic architecture, demographics, family and medical history from April 2020-April 2021. 30/101 cases (29.7%) on WES (whole exome sequencing) showed pathogenic/ likely pathogenic variants.

Results: Family history (1st/2nd degree-relatives) of developmental and/or medical concerns was noticed in 38.61% cases with 28.71% having predominantly developmental/behavioral concerns (psychiatric-disorders, learning-disability, language-delay, autism, aggressiveness). Medical concerns documented were seizures, hydrocephalus, spina-bifida, trachea-esophageal fistula, neonatal deaths.

49.5% of the cohort had sibling/s with 7.9% having twins/triplet. 22% of siblings had developmental concerns (autism, learning-difficulties, speech-language delays). For multiple pregnancies, developmental delays were noticed in 62.5%.

ASD was observed in 16% of sibling. In multiple pregnancy 50% had ASD, for siblings the incidence was 8%. Overall positive family history of ASD was observed in 12.8% of total cohort.

Conclusion: Family histories of developmental delays and its association to socio-demographic and medical parameters can help to identify the risk factors- both genetic and epigenetic, playing a role in the increasing prevalence of ASD. This can help in better counselling and management, especially important for socially and culturally diverse countries like India.

Relevance for users and families:

Probability of having ASD is estimated to be 40-80% genetic with epigenetics playing a role via modifying the environmental factors. The study highlights the increase incidence of developmental disorders, including ASD in siblings and family members. This in turn highlights the need to study environmental factors like consanguinity, endogamy and medical factors like pregnancy complications, quality of antenatal care etc which may be contributing to the increasing incidence in families.

Early motor, cognitive, language, behavioral and social emotional development in infants and young boys with Duchenne Muscular Dystrophy- a systematic review

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Introduction: Duchenne Muscular Dystrophy (DMD) is an X-linked recessive disorder caused by mutations in the dystrophin gene. Deficiency of the dystrophin protein Results not only in motor problems, but also cognitive, language, behavioral and social emotional problems. The aim of this systematic review was to investigate 1) early developmental domains in young boys with DMD between 0 and 6 years old and the interaction between them and 2) the link with mutations.

Method: A systematic search was performed in Pubmed, Web of Science and Scopus. An adapted version of the Scottish Intercollegiate Guidelines Network (SIGN) Checklists for case-control and cohort studies was used for quality evaluation, and the level of evidence regarding Portney and Watkins was determined.

Results: Fifty-five studies of acceptable or high quality were included. One study was an RCT of level 1b; 50 studies were cohort studies of level 2b; and four studies were case control and cohort studies of levels 2b-3b. When investigating early development in preschool boys with DMD, most studies pay attention to gross motor development. Young boys with DMD still gain in function, yet they score lower compared to healthy children. A link between loss of dystrophin in the brain and cognitive delays has been found. Few studies report on early language, behavioral and emotional development.

Conclusions: DMD is characterized by a global developmental delay with a large variability between boys. However, more high-quality research is needed regarding the early developmental domains to provide better alertness of symptoms and associated early intervention strategies.

Relevance for users and families:

Data on the five different developmental domains are still scarce and a large variability in phenotypes of Duchenne Muscular Dystrophy (DMD) is found. Better insights in these different phenotypes and relations with the different types and sites of mutations seen in DMD could provide a better overview of early development in this population. Furthermore, these insights might contribute to earlier detection of difficulties, facilitating early intervention strategies adapted to the individual young boy with DMD.

Impacts on children and young people with long term disability of health care service changes implemented due to COVID-19: a mapping review

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Introduction: The nature and extent of COVID-19 restrictions and changes to disabled children's services and their effects is yet to be comprehensively evaluated. This mapping review aimed to identify research on childhood disability service adaptations and their impacts and detect gaps in our understanding.

Patients and Methods: We searched the WHO Global COVID-19 database, using the main concepts of 'children', 'chronic/disabling conditions', and 'services/therapies'. Eligible papers reported changes in services for children (0-19 years) with long term disability; in any setting or geographical location between 1st January 2020 to 26th January 2022. We charted papers using the Effective Practice and Organisation of Care taxonomy of health systems interventions, and synthesised findings narratively and in an interactive evidence map.

Results: Child and family health and wellbeing were negatively impacted by reductions in face-to-face care and usual provision. Telehealth provided continuity of some care, but was more suited to medically-led care than allied health. Changes in mental health services, transitions of care and social care, or child-reported satisfaction or acceptability of service changes were rarely reported.

Conclusions: The long-term impacts of change in services during the pandemic are still to be fully evaluated. However, the widespread disruption seems to have had a profound impact on child and carer health and wellbeing. Service recovery needs to be differentiated to the specific individual needs of children with disability and their families. This should be done through coproduction with families to ensure changes meet needs, are accessible and equitable so health disparities are not exacerbated.

Relevance for users and families:

The findings of this review highlight what is and is not understood about delivering care to disabled children in times of emergency. Gaps in the current research of the impacts of the pandemic on services and families have been identified. This mapping review is part of a broader project including interviews with professionals and parent carers in England and a survey designed to provide essential recommendations for services to disabled children in times of emergency.

ENVISAGE-First Peoples: Empowering caregivers through collaboration, connection, culture and community

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Introduction: ENabling VISions and Growing Expectations (ENVISAGE) First Peoples is a caregiver, community, service provider, and researcher collaboration developed to integrate research evidence, clinical experience, caregiver and community knowledge/expertise, to empower caregivers raising Aboriginal and Torres Strait Islander children with a disability. ENVISAGE First Peoples aims to enhance family well-being; build caregiver confidence and strengthen families; and support connection to culture. We aimed to connect with Aboriginal and Torres Strait Islander families, communities, and service providers using traditional yarning circles to build partnerships and discuss project co-design.

Patients and Methods: ENVISAGE uses a multiple-method, five-phase, integrated knowledge translation approach, to foster culturally responsive, consumer-driven research in the review, creation and evaluation of the program. In this phase, we yarned with families to understand their experiences of raising a child with a disability and explored the extent to which ENVISAGE, and its foundations could have perceived value and meaning to families.

Results: Families told us about the difficulties in seeking help and relevant information from health professionals upon diagnosis. They relied extensively on family support but needed more skills and knowledge to navigate the complex health, disability, and education systems. Families thought the ideas in ENVISAGE were relevant and useful but needed to better reflect the diverse culture and experiences of Indigenous Australians and focus on cultural connections and community.

Conclusion: Families endorsed moving forward with the next phases of ENVISAGE to co-design and co-produce a culturally-responsive program for Aboriginal and Torres Strait Islander families and communities called ENVISAGE First Peoples.

Relevance for users and families:

This work discusses a research project focused on establishing partnerships and co-design with people with lived experience, their families and communities. People interested in family engagement in research and researcher-consumer partnerships may find this work interesting. This project is also about improving the wellbeing of families and communities raising children with developmental difficulties or concerns. It focuses on Aboriginal and Torres Strait Islander People from Australia.

A qualitative study investigating the experiences of unmet social needs for children with cerebral palsy and their families

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Introduction: Unmet social needs can impact health and wellbeing outcomes for children with cerebral palsy (CP) and their families. There is no published research exploring the individual experience of unmet social needs of this group. The aim of this study was to understand the impact of unmet social needs on families of children with CP and the enablers and barriers to addressing these needs, as described by families and their clinicians.

Patients and Methods: This study utilised qualitative methodology through 1:1 semi-structured interviews with parents of children with CP and semi-structured focus groups with clinicians working with children with CP. Purposive sampling was used to obtain perspectives from parents of children with CP of varying ages, gross motor abilities, and differing cultural, linguistic, and socioeconomic backgrounds. Purposive sampling of clinicians was used to include a range of disciplines. Interviews and focus groups were recorded and transcribed verbatim before being thematically analysed.

Results: A total of 43 participants (8 parents, 35 clinicians) participated. Four main themes were identified: (1) Unmet social needs are pervasive; (2) A broken system with systemic downfalls and no roadmap; (3) Unmet social needs impact through all aspects of life; (4) It takes a village to raise a child.

Conclusion: Overall, unmet social needs are pervasive, with profound impacts on all aspects of an individual and their family's lives. Families were empowered by community, clinicians, and personal resilience in receiving help, but hindered by a difficult to navigate system with inequitable access and quality of services.

Relevance for users and families:

This study highlights the profound impact of unmet social needs on daily life. This is further compounded by the additional complexities of raising a child with disability, the domino effect of multiple unmet social needs accumulating and further disadvantaging families, and the difficulty navigating complex health and social care systems. It emphasises the importance of systematically identifying unmet social needs in clinical care with enhanced pathways to support families to navigate systems and access services.

The investigation of the relationship among the function levels and proxy-reported quality of life in children with severely affected dyskinetic cerebral palsy

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Introduction: The study aimed to investigate the relationship between function levels and proxy-reported quality of life (QOL) in severely affected children with dyskinetic cerebral palsy (dCP).

Materials and Methods: Fourteen children with dCP aged between 5-18 years were included. Function levels, functional classification systems; QOL were evaluated with the Cerebral Palsy QOL Questionnaire Child and Adolescent (CP QOL Child-Teen). This study received ethical approval (GO-22/535). Spearman's correlation test was used to evaluate the relationship among data.

Results: The mean age was 12.50±3.77. A good correlation (rs=-0.62, -0.64) between the Gross Motor Function Classification System, and the CP QOL Child-Teen Social; Funtioning; Participation; Emotional; Pain score were found (p=0.016, 0.012, respectively). A moderate correlation correlation (rs=-0.57, -0.54, -0.53, -0.58) between the Visual Function Classification System, and CP QOL Child-Teen Social; Funtioning; Emotional; Pain score were found (p=0.033, 0.045, 0.047, 0.029, respectively). A moderate correlation (rs=-0.55) between the Viking Speech Scale (VSS), and the CP QOL Child-Teen Emotional score were found (p=0.038). There was also excellent correlation (rs=-0.81, -0.90, -0.84) between the VSS, and CP QOL Child-Teen Participation; Emotional; Pain score in children with dystonia overflow movements (p=0.026, 0.005, 0.017, respectively). No correlation was found in children with choreoethoid overflow movements.

Conclusions: In Conclusion, the Results suggest that gross motor skills, communication and visual function might predict QOL in dCP. From a clinical point of view, our Results highlight the importance of considering functional levels as part of intervention programs designed to improve the QOL of children with dCP.

Relevance for users and families:

The work presented here is relevance parents to people with lived experience, their family members and others involved.

Variation and adaptability of motor behaviour are associated with cognitive function in extremely preterm born infants

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Introduction. Extremely preterm born infants are at risk for impaired cognitive development, even in the absence of an evident brain lesion. Identifying infants at higher risk for cognitive impairments remains a challenge. Movement variation represents the size of the motor repertoire and is thought to reflect the integrity of cortical connectivity, whereas the adaptability of motor behaviour may mediate cognitive function. The aim was to investigate associations between variation and adaptability of motor behaviour in early infancy and cognitive performance at 2 years of corrected age (CA).

Patients and Methods: Participants were 85 extremely preterm born children (44 females, 41 males; mean gestational age 26 weeks) with no evident brain lesion on MRI. Variation and adaptability of motor behavior were assessed at 12 months CA with the Infant Motor Profile (IMP). Cognitive outcome was measured with the Bayley Scales of Infant and Toddler Development (Bayley–III) at 2 years CA. Associations between variation and adaptability IMP scores and Bayley cognitive scores were assessed using correlation coefficients and linear regression.

Results: Correlations of the variation and adaptability IMP scores with the Bayley-III cognitive scores were .78 and .85, respectively. Higher variation and adaptability IMP scores were associated with better cognitive performance.

Conclusion: Our study suggests that variation and adaptability of motor behaviour in early infancy are associated with cognitive performance at 2 years of CA in extremely preterm born infants. Reduced movement variation and adaptability may alter the cognitive developing process in infants born extremely preterm.

Relevance for users and families:

This underscores the importance of early identification of infants at high risk for cognitive impairments and comprehensive health policies targeting preterm infants to promote optimal neurodevelopmental outcomes.

Experiences of occupational therapists and teachers of their school-based collaboration applying an early intervention approach to enable participation of all children

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Introduction:The problem of inequality and exclusion is high priority, especially for children. Joint collaboration between teachers and occupational therapists has shown promise as a strategy to enhance teachers' capacity to enable inclusion of children in elementary schools and to prevent individual child services. We applied the Canadian Partnering for Change (P4C) model as a collaborative, coaching- and context-based approach in the Netherlands and Sweden. The aim of this research study was to gain insight into teachers' and occupational therapists' experiences of their joint collaboration.

Patients and Methods: To this end, we held semi-structured interviews with 4 teachers and 4 occupational therapists and performed a conventional, inductive content analysis including several international debriefing sessions.

Results: We found that participants' collaboration in the classroom context was a continuous, multi-stage process that we defined as a unique mastery journey toward collaborative learning and trustful partnership. Participants indicated that they needed time to become familiar with the new collaboration, how they learned from each other, and that they enhanced children's inclusion by applying strategies collaboratively.

Conclusion: The Results carry implications for the embedment of collaboration in schools and offer relevant strategies that serve the inclusion of all children from a more preventive perspective.

Relevance for users and families:

This work is highly relevant for professionals that aim to enable children with special needs as building teachers capacity to enable inclusion in their classrooms could increase children's involvement in all school activities. Furthermore, several additional individual services could be avoided by using this preventive approach.

Socio-emotional stress regulation in visually impaired infants - An observational and eye-tracking study

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Introduction: early parent-child interactions are essential for socio-emotional development, sustaining abilities such as Socio-emotional stress regulation (SESR). Dyadic interaction strongly relies on vision, mediating reciprocal interpretations of emotional signs. Visually impaired (VI) children may present unclear emotional cues and fail to interpret their parents' non-verbal behaviors. This study aims to 1) compare typically developing (TD) and VI infants' SESR, 2) explore the role of mothers' voice and touch, (3) compare observational patterns of VI and TD infants' mothers during a task of child's emotion recognition.

Patients and Methods: 9-to-12-month VI (n=15) and TD (n=10) infants and their mothers participated in a videotaped Face-to-Face Still-Face (FFSF) session. Subsequently, mothers were shown videos of their infant expressing positive or negative emotions on a Tobii TX300 eye-tracker. Infants' negative emotionality and avoiding gaze and mothers' verbal and touching behaviors were micro-analytically coded.

Results: Preliminary data showed higher negative emotionality and avoiding gaze during still-face phase in both groups. Mothers of TD infants decreased the use of playful touch after the still-face phase, in favor of mind-oriented verbal comments. Looking times proportions to the child's body-vs-face and eyes-vs-mouth were similar between groups.

Conclusion: VI and TD infants seem to be similarly sensitive to maternal unresponsiveness. VI infants' mothers seem to use similar observational patterns to read their infant's emotional needs and use less mind-oriented and more playful tactile stimulations when regulating their infants SESR. These data offer potential targets for early interventions to sustain infants' socio-emotional development and mental health through early dyadic interaction.

Relevance for users and families:

The benefits of parental engagement in early intervention are well known. From a family-centred perspective, understanding the peculiarities of dyadic interaction and regulation patterns between visually impaired infants and their caregivers is essential. Our preliminary data suggest the existence of specific patterns that could be sustained, providing parents with strategies to help their infants' regulation in everyday life. On the other hand, facilitating dyadic interactions would foster the child's socio-emotional development.

Supporting children and young people with Learning Disabilities and/or Autism to feel safe and be safe in hospital: the development of a risk assessment instrument

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Introduction: Children and young people with learning disabilities and/or Autism often have significantly higher care needs than other children, including more health conditions and more frequent and lengthier hospitalisations, which can be extremely challenging and anxiety-provoking for them and their parents. Research has identified healthcare professionals' concerns about their capability, confidence and capacity to identify and meet the needs of these patients in hospital, including delivering safe care. Parents also report concerns about their child's safety in hospital, expressing a need to always remain hypervigilant. We developed an evidence-based risk assessment instrument with the aim of maximising the safety and well-being of children and young people with learning disabilities and/or Autism in hospital.

Patients and Method: A mixed Methods design was utilised, comprising a scoping review of the literature (n=132 full text papers), retrospective review of hospital-related complaints, and focus groups and workshops with parents (n=13) and hospital staff (n=29). A child and young person's advisory group and parent advisory group met throughout.

Results: A risk assessment instrument was developed incorporating thirteen care domains, and associated reasonable adjustments, identified as relevant to the delivery of safe hospital care to children and young people with learning disabilities and/or Autism. A traffic light scoring system was included for rating potential risks to a child's or young person's emotional and physical health and well-being when reasonable adjustments are not implemented, Also included were composite scores to inform clinical decision-making. The instrument was deemed to have potential for use in an adult care setting.

Relevance for users and families:

The routine and proactive use of this risk assessment instrument has the potential to support children and young people with learning disabilities and/or Autism to feel safe and be safe in hospital. We believe it can support the delivery of high quality, compassionate care through empowering healthcare professionals to confidently identify and implement necessary reasonable adjustments to these patients, thereby helping parents to feel more confident about leaving their child's bedside when they need to.

Partnership-focussed Principles-driven Online co-Design (P-POD): evaluation of a novel process for authentic stakeholder engagement.

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Introduction: Involving stakeholders in intervention design leads to better solutions, enhanced relevance to user needs, increased user satisfaction, and improved uptake of health-care initiatives. Co-design is a process that engages stakeholders as equal partners in research and has a growing body of evidence for its effectiveness in producing meaningful interventions and positive participant experiences. Traditionally undertaken through face-to-face workshops, the COVID-19 pandemic challenged co-design to move into an online environment. P-POD (Partnership-focussed Principles-driven Online co-Design) was developed to ensure an authentic co-design experience in an online context. This study seeks to evaluate P-POD's adherence to co-design principles and explore the experience of the stakeholders involved.

Methods: Parents of children born preterm (n=4), clinicians (n=2), coaches (n=2), and clinician-researchers (n=2) were involved in the P-POD process. A convergent mixed-Methods evaluation design was chosen with quantitative data collected via surveys at the end of each of the eight co-design sessions (n=46 responses), and qualitative data collected via semi-structured interviews (n=7). Data were analysed via descriptive statistics and reflexive thematic analysis.

Results: All participants were retained and reported 100% engagement and 100% satisfaction with P-POD. 98% of responses indicated adherence to co-design principles. Participants felt the process had been successful in achieving its goal and had attained knowledge and experience that was meaningful to them.

Conclusion: P-POD shows promise as an authentic co-design process which enables stakeholder engagement to enrich health research regardless of COVID-19 restrictions and capitalises on the convenience and accessibility that online approaches provide.

Relevance for users and families:

There is a growing call from stakeholders (such as parents of children with disability) to be involved in all aspects of health policymaking, clinical care, and research, including intervention design. Online co-design strategies provide increased accessibility for stakeholders to be involved in research that affects them. Accessible, authentic, and meaningful co-design processes are important for future research seeking to collaboratively design health interventions.

Being a child with learning disabilities in hospital: 'I've just got to get out of here'

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Introduction: Despite their increased likelihood of attending hospital compared to other children, there is a limited body of in-depth, multi centre qualitative research focussed specifically on what it is like for children and young people with learning disabilities to be an in-patient, with much of the evidence-base being about children with Autism or adults with learning disabilities. We highlight in rich detail the emotional and physical impact on children with learning disabilities of being hospitalised from their own and their parent's perspective.

Patients and Methods: Forty-two families of children and young people with learning disabilities took part. Children and young people with learning disabilities were invited to undertake an interview using Talking Mats, a sticker survey and/or photography. Children could indicate their views and preferences verbally, through pointing or eye gaze, using communication software or with the help of their parents as communication partners. In-depth interviews, hospital diaries and/or photography were utilised to elicit views from parents. Parent and children's interview data were analysed using reflexive thematic analysis.

Results: The multiple and compounding layers of complexity surrounding their care resulted in specific issues associated with loss of familiarity and routine, undergoing procedures, managing sensory overload, managing pain and having a lack of safety awareness. There was a combined sense of fear, distress and desperation across much of the data that extended to parents' own experience as well as that of their child. Supporting families early in their hospital journey through a proactive, individualised approach to care is needed.

Relevance for users and families:

Narratives from experts by experience enhance staff training and positively impact changing practice. The personal accounts provided in this presentation can help healthcare professionals to a) understand the reality of the impact that seemingly innocuous, as well as more significant, hospital experiences have on the well-being of children with learning disabilities and their families, and b) support them to meaningfully engage with and deliver Learning Disabilities/Autism Awareness training, which is now mandated within the UK.

Participation in Home Routines and Family Quality of Life in 1-Year-Old Children with Risk Indicators for CP.

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Introduction: Follow-up programs for children with "high-risk of cerebral palsy" (CP) or CP, aim to impact access to care and long-term health outcome. However, their implementation is gradual and affected by different barriers (system or social factors, health professional knowledge, perceptions). Our study aims to describe participation in home routines and family quality of life patterns in 1-year-old children with risk indicators for CP who didn't follow international clinical practice guidelines for early detection.

Patients and Methods: A prospective observational case series study of infants with identifiable high-risk indicators in the newborn period was conducted. They attended the Hospital Universitario Insular Materno Infantil (Las Palmas de Gran Canaria, Spain) and the Hospital Universitario de Toledo (Toledo, Spain). Infants were born between May 2021 and April 2022. The primary outcome was the Measure of Engagement Independence and Social Relationships (MEISR) which measures the participation of children in home routines. Families' functioning in their natural environment was assessed through the Families in Early Intervention Quality of Life (FEIQoL). Eligibility decisions for referral to early intervention services and age at referral were also collected.

Results: Since May 2022, 29 families of children at 12 months of corrected age have completed the MEISR and FEIQoL. Participation in home routines and family quality of life will be correlated with the referral or not to the early intervention system, and with age at referral.

Conclusion: Preliminary Results of this study suggest that delay or non-referral to early intervention impacts participation and family quality of life.

Relevance for users and families:

Perceived delays in referral to early intervention could be associated with potentially worse outcomes in infants' and children functioning, and family quality of life.

The PIH Multi research study - RCT protocol

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Introduction: PIH Multi is an intensive multidisciplinary rehabilitation program for preschool children with neurodisabilities, including severe motor impairments. The program involves parents and local professionals and includes individualized goal setting and group treatment. PIH Multi is delivered over a period of one year, including three two-week inpatient group sessions (4 – 6 children). Between inpatient sessions local professionals deliver one hour individualized daily training based on Goal Attainment Scaling. PIH Multi has been offered by the Regional center for intensive child rehabilitation (RIC) at Sørlandet Hospital, for more than 20 years and is now being implemented in all health regions of Norway through a multicenter research study.

Aim / Patients: To evaluate effectiveness of the PIH Multi program, specifically preschool children's adaptive skills and functioning and parental empowerment and stress.

Method: This is a multicenter Randomized Controlled Trial (RCT) with blinded evaluation by independent researchers, combined with questionnaires filled out by parents at baseline, pre- and post-training. Primary effectiveness measures are PEDI-CAT and Family Empowerment Scale for children and parents, respectively. A stepped-wedge design is applied in order to offer the invention program to all participants. We plan to include 90 children and their parents. Two separate PhD projects will focus on effects for children and parents.

Conclusion: If the project creates scientific evidence for the beneficial effects of this Norwegian model of intensive rehabilitation in preschool children with brain injury, this service should be offered as a supplemental regional clinical multidisciplinary program to all Norwegian children with severe neurodisabilities.

Relevance for users and families:

The PIH Multi program of intensive rehabilitation for preschool children with brain injury, will be offered as a supplemental regional clinical multidisciplinary program to all Norwegian children with severe neurodisabilities. The program is based on family centered research and care and we predict beneficial effects for both children and parents after participation.

PIH Multi – national implementation of an Intensive child rehabilitation program in Norway

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Introduction: PIH Multi is an intensive multidisciplinary rehabilitation program for preschool children with neurodisabilities, including severe motor impairments. The program involves parents and local professionals and includes individualized goal setting and group treatment. PIH Multi is delivered over a period of one year, including three two-week inpatient group sessions (4 – 6 children). Between inpatient sessions local professionals and parents deliver one hour individualized daily training based on Goal Attainment Scaling. PIH Multi has been offered families in the southern region of Norway, by the Regional center for intensive child rehabilitation (RIC) at Sørlandet Hospital for 20 years. Children in other health regions of Norway are not offered PIH Multi.

Aim: To implement PIH Multi in the other health regions of Norway

Method / Results: RIC have produced documentation of theoretical background, clinical experience, training sessions, user evaluation, patient logistics, letters, forms and lectures used in the program. This is administered to all centers starting the program in their respective health regions. RIC then hosts lectures and workshops, visit and counsel professionals at other centers and receive interns. Parallel to implementation of PIH Multi, a multicenter randomized controlled trial is carried out to evaluate effectiveness of the program.

Conclusion: This project reduces inequalities in health services between regions in Norway. A successful method of implementation can serve as model for cooperation between health regions and national implementation of treatment services. Eventual scientific evidence for beneficial effects of the PIH Multi program will serve as an additional indicator of successful implementation.

Relevance for users and families:

This project reduces inequalities in health services between regions in Norway. Further, Results from the project will aid us in the development of a model for cooperation between health regions and national implementation of treatment services.

Enhancing Social Participation of children with hemiplegia: the Explorers Project

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Introduction: Children with hemiplegia are at risk of reduced social competence and self-esteem with possible psychiatric disturbance that may have greater and more long-lasting impacts than the motor impairment. This study explored the impact of intensive motor learning interventions on participation and well-being for children with hemiplegia.

Patients and Methods: Within-subject experimental design involving 28 children with hemiplegia aged 3 to 9 years, Manual Ability Classification Scales (MACS) I-III, participated in one of three day-camps in Cardiff (UK) or Milan (Italy). focusing on (upper-limb) function, fitness and fun. Assessments undertaken before, immediately and 6-months after the camp included: Child and Adolescent Scale of Participation (CASP), Strengths and Difficulties Questionnaire (SDQ) and Children's Hope Scale. Descriptive and inferential statistics explored effects of intervention on participation and psychosocial outcomes, controlling for age and ability (MACS) using repeated measures ANOVA.

Results: Outcomes showed increased participation that did not reach significance (CASP: F(2,22)2.96,p=.073). HOPE (resilience) showed a trend for sustained benefit (F(1,25)2.74,p=.087). There was no overall reduction in psychosocial problems (SDQ: F(2,24)369,p>.05) although 5/28 children were rated as having abnormal scores prior to intervention, as opposed to 2/28, six months later. An interaction effect of HOPE and CASP was evident with positivity associated with better participation outcomes (F (1,21) 3.87,p=0.037), without effect of age or MACS level.

Conclusion: Findings reflect complex interactions between the child, psychosocial factors, self-esteem and resilience. Interventions to improve motor skills should consider broader impacts of disability in childhood, and in particular focus on improving social participation ere outcomes.

Relevance for users and families:

Social participation is reduced for many children with hemiplegia and or cerebral palsy. There is a complex and dynamic interaction between the individual, context and environment contributing to participation. These Results support the inclusion of participation, self-esteem and well-being measures when considering outcomes of interventions.

Parental report of early markers of developmental coordination disorder (DCD)

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Introduction: Parents of children with Developmental Coordination Disorder (DCD) often express concerns long before their children receive their diagnosis. However, knowledge on early signs of DCD is limited. A better understanding of the early development could enhance the diagnostic process and facilitate adequate early support. This study aimed to explore parental-reported early markers of DCD from birth up to 5 years.

Patients and Methods: Semi-structured interviews were conducted in parents of 12 children diagnosed with DCD. Parents were asked to talk about their child focusing on the period between birth and five years of age. Up to three interviews were performed of each participant with a duration between one and three hours. The interviews were then transcribed ad-verbatim and analyzed using an inductive thematic analysis approach.

Results: Parents described poor quality of motor milestones, early difficulties in activities of daily living, altered play and exploration behavior, variations in tone, higher levels of fatigue and disturbed sleeping, reduced participation, altered sensory processing, early socio-emotional challenges and articulation difficulties. Differences in the child's context were described such as searching for an explanation, providing adaptations, specific choices in participation, concerns of other caregivers, and increased family stress.

Conclusions: This study highlights that many of the typical DCD 'traits' are already observable at an early age and that parental interviewing is highly interesting to explore difficulties concerning criterion B in very young children. The Results stress the importance of conducting a thorough in-depth anamnesis in children with a risk of DCD.

Relevance for users and families:

The Results of this study may facilitate earlier detection of developmental coordination disorder and enable early support by providing important topics to discuss in an in-depth parental anamnesis. More knowledge on the early presentation of DCD is necessary to interpret the observed behavior correctly. The Results emphasize that we should not focus too much on when children achieve developmental milestones, but rather on how they do it.

Exploring participants' experiences of participation in a feasibility randomised controlled trial of an interactive training device: a qualitative interview study.

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Introduction We conducted this study to understand the experiences and views of children with cerebral palsy, their parents and physiotherapists participating in the ACCEPT feasibility randomised controlled trial. ACCEPT explored a 10-week physiotherapy intervention using the Happy Rehab™ (Innovaid, Denmark) interactive gaming training device.

Patients and Methods: We used qualitative Methods including semi-structured interviews, e-diary, and photographs. We interviewed nine parent- child dyads and three physiotherapists. The children were aged between 7-16 years. Interviews were transcribed. Data were coded into categories and themes using thematic analysis.

Findings: Five themes were identified: (1) Fitting therapy into normal life- Parents spoke of the challenge of finding time to engage their children in therapeutic exercise. (2) Motivation to exercise- Participants felt that gaming would improve adherence to therapeutic exercise. (3) The opportunity to try something new- The Happy Rehab was welcomed as a change from physiotherapy routines described as 'boring and repetitive.' (4) Physiotherapists out of their comfort zone- Physiotherapists were unsettled by the unfamiliar equipment. (5) Altruism and the challenge of participating -Several children talked about trial-related procedures that they disliked (e.g., removing adhesive skin tape).

Physiotherapists, children, and parents supported the gaming aspect of Happy Rehab to improve motivation to exercise.

Conclusions: Children found the gaming aspect motivating and enjoyable. Some families raised issues about accommodating the device at home or within an educational setting. Physiotherapists required more technical support with the device.

Relevance for users and families: Exercise trainers that encompass gaming may increase motivation and adherence to therapeutic programmes.

Relevance for users and families:

Exercise trainers that encompass gaming may increase motivation and adherence to therapeutic programmes. Families, children and physiotherapists contributed to designing a future randomised control trial which would be feasible to run and acceptable to them.

Pediatric physiotherapists' perceptions about their use of scientific evidence in clinical decision-making. An observational cross-sectional study in Spain.

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Introduction: During the last decades, it has been recommended that physiotherapists increase evidence-based practice behaviors as a way of translating research evidence into clinical practice. The objective of this work is to know the beliefs of pediatric physiotherapists about whether they use evidence-based practice in their treatments, the evaluations of their patients and what importance they give to this use.

Patients and Methods: An observational and cross-sectional study was carried out in Spain. The data was obtained through an electronic survey, including questions on three thematic blocks: sociodemographic characteristics, perceptions of the use of evidence in clinical decision-making, and the importance given to that use.

Results: 425 responses were obtained. 91.5% were women, 68.8% under 40 years old. 12.9% stated that they always used evidence-based interventions, whereas 49.5% used them often. Regarding the standardised assessment tools, 22.1% used them always, and 39.4% did it often. 9% did not use assessment tools, and 26.7% were not sure about the evidence of their tests. Surprisingly, 85.9% of respondents said they gave great importance to the use of scientific evidence in clinical decision-making. Younger physiotherapists gave greater importance to the implementation of scientific evidence in their treatments (p=0.002), while gender did not show a significant relation.

Conclusions: Pediatric physiotherapists gave great importance to the use of the evidence-based practice, however, many of them do not use it in their treatments or assessments. It is important for the profession that physiotherapists develop skills to use scientific evidence in the care of children.

Relevance for users and families:

Using evidence-based practice should be mandatory for health professionals caring for children. Increasing professionals' skills in using scientific evidence could improve the Results of treatments.

A comparative analysis of Family Pathology among families having Neurodivergent and Neurotypical children

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Introduction: Family environment involves the circumstances and social climate conditions within families. Parents' interpersonal relationship is at the center of the family system, which influences all aspects of family functioning. Parents' ability to communicate effectively, generate emotional closeness, and support each other's decisions has implications for their children's well-being and development.

Patients and Methods: Mixed-method approach has been utilized for collecting data from- 50 families with Neurodivergent children via case histories and 50 families with Neurotypical children via Family Pathology Scale.

Results: In the neurodivergent group, 38% of people reported having high family pathology (19); 18% had moderate family pathology (9); 48% had low family pathology (24). In the neurotypical group, 14% reported high family pathology (7); 68% had moderate family pathology (34); 18% had low family pathology (9). High family pathology indicated maternal stress during pregnancy and frequent instances of verbal and physical abuse in their home environment. Moderate family pathology indicated instances of mood disturbances, anxiety, loneliness, and stress. Low family pathology indicated no significant distress in the family environment and family members exist together in harmony. Overall, families with neurodivergent children face more issues that cause significant distress and hamper daily functioning. The existence of family pathology is detrimental to the well-being of children, hence obtaining psychoeducation and counseling can improve the situation.

Conclusion: This study focuses on understanding the presence of family pathology in families with Neurodivergent and Neurotypical Children and seeks to promote the importance of taking care of parents' mental health.

Relevance for users and families:

Family should be a safe space for all children. The existence of family pathology would lead to adjustment and trust issues among members, which would further yield low self-confidence and lead to impaired development in children. Neurodivergent children have more issues in building rapport and in adjustment, hence such conditions would be deleterious for them.

Adapting a participatory intervention for caregivers of children with complex neurodisability from low resource to high income settings: Moving from "Baby Ubuntu" to "Encompass"

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Background: "Baby Ubuntu" is a community-based intervention for families of young children with cerebral palsy (CP), that has been developed and tested in low-resource settings globally. The programme provides caregivers with support to increase their skills and confidence to care for their child and promote development, enhancing the impact of early intervention.

Methods: "Baby Ubuntu" is being adapted for use in East London, UK as "Encompass", in line with the ADAPT and MRC complex intervention development frameworks. Stakeholder engagement was achieved using an advisory group, including the original creators of the intervention, and a Patient and Public (PPI) Involvement group. The adaptation team consisted of the researchers, advisors, and PPI participants. Semi-structured interviews were conducted with 12 caregivers and 6 healthcare providers of children with CP.

Results: Data from the qualitative interviews were analysed and considered by the adaptation team. It was felt that content should include greater emphasis on caregiver mental health and well-being, signposting to third sector organisations, simplifying medical terminology, and educational support. Key programme delivery recommendations included joint facilitation with health specialists and expert parents, considerations of language and cultural diversity, and a blended face-to-face and online delivery. A logic model and adapted manual was drafted based on this feedback.

Conclusions: The adaptation described is one of few examples where an intervention is being adapted from a low-resource to a high-resource setting. "Encompass" has been co-developed with various professionals and parents with lived experience to improve its relevance and impact. Next steps include pilot implementation evaluation.

Relevance for users and families:

The co-adaptation from "Baby Ubuntu" to "Encompass" included those with lived experience throughout the process. This was to ensure that the adapted intervention manual would be relevant and impactful for the service users. The families and children with complex neurodisability who attend the "Encompass" groups in the pilot study will learn practical skills in caring for their child, build confidence in their abilities, and forge peer support networks to encourage information sharing and emotional support.

Developing and implementing a Standard of Care for psychosocial care in pediatric rehabilitation: WHAT, HOW and NOW?

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Learning Objectives:

- Learn about patients' and parents' perspectives on psychosocial care in pediatric rehabilitation.
- Learn about the current literature on psychosocial care in pediatric rehabilitation, and the translation into recommendation into the Standard of Care .
- Get inspired on ways to implement the standard of care.

Target Audience: Healthcare professionals in rehabilitation teams with interest in improving the psychosocial care provided to children and their families, and parents/familymembers of children with disabilities

Summary: In pediatric rehabilitation care, the focus is on development and participation of children with disabilities. It is recognised that psychosocial functioning of the child and other family members are important in development and participation. However, children and parents feel that there is not enough emphasis on psychosocial support and care, whereas professionals often report it is challenging to address these issues well. To support the implementation of knowledge related to psychosocial care, in the Netherlands the parent association initiated the development of the National Standard of Care for Psychosocial Care in Pediatric Rehabilitation, in a joined effort of parents, young persons with disabilities, researchers, and health care professionals. Starting with questions derived from interviews and focus groups with all stakeholders, an extensive literature research was conducted on five themes: Information, the child's functioning, parents, other family members, and the social environment.

Outline of the course: We will present the Standard of Care, including recommendations, and discuss strategies for and experiences with implementation into daily practice, including the toolbox and monitor for teams and families.

Relevance for users and families:

By implementing this parent-driven, evidence-based standard of care, rehabilitation teams can improve the psychosocial care provided to children and their families. Moreover, families can actively ask for psychosocial care when informed about this standard.

KAP survey and program evaluation on low Vision Rehabilitation and vision therapy

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Background: It was noticed that there were no vision therapy services provided in Bangladesh. Although there was a considerable requirement for both vision therapy as well as low vision rehabilitation. Low vision rehabilitation services existed in a fragmented way, however, there was no VT training or services available across the country.

Methodology: A tertiary eye hospital was selected in the capital city Dhaka. 10 optometrists were trained through a structured training program. VT and LVR services were introduced in the hospital and a KAP (knowledge, attitude and practices) survey was conducted to understand the success of the program and its relevance to the population of Bangladesh. Respondents were randomly selected 404 patients who underwent evaluation and VT. The questions were based on qualitative and quantitative questionnaires which were formulated through FGD and validated using statistical Methods.

Results: Knowledge about eye health and awareness of signs and symptoms of various eye conditions increased considerably. Social stigma associated with ocular problems and the patients' behavior towards them changed positively. Awareness of VT services was greatly enhanced and the 57.7% patients who were surveyed benefitted from VT. And 95.3% were satisfied. 99.3% respondents were willing to refer patients for VT.

Conclusion: There is a need for vision therapy and low vision rehabilitation services in all the countries. The drawback is adequate training. It was concluded that structured training of the professionals with provision of VT services will go a long way in assuaging the symptoms and improving quality of life of the patients.

Relevance for users and families:

VT services are required in every country. The services help the children in visualizing properly which complements other therapies bringing a much-desired result.

Barriers in biopsychosocial model implementation in pediatric disability rehabilitation in Moldova.

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Introduction:The biopsychosocial model is the holistic approach in pediatric disability rehabilitation, designed to address the child's and family's experiences of disability and it replaced the biomedical approach. Moreover, the Family-Centered Care (FCC) was developed - the ideal service delivery in pediatric rehabilitation. The baseline is the multidisciplinary consultation where the family is the decision-making team member.

Patients and Methods: A qualitative study based on three focus-groups analyzing the practices and attitudes of 1. The parents; 2. Medical specialists (doctors, nurses, physical therapists); 3. Psycho-pedagogical staff. The questions were structured in four chapters: 1. Multidisciplinary approach; 2. Parents implication; 3. Major issues confronting; 4. How to improve the experiences and outcomes.

Results: The data analyses showed that the barriers were on the both sides – specialist's and parents. Almost half of the parents claimed that they have no necessary knowledge to be a part of the team and diagnosis and prognostics info is not provided by the specialists. Specialists claimed that the parents' presence at the consultation prevents them to speak freely in respect of the child's future and possible complications.

Conclusions The theoretical knowledge in respect of the biopsychosocial approach is proven to be insufficient, thus a series of training with adapted curricula was created, targeting the medical and non-medical specialists. Moreover, we organized teaching activities with families and group activities with the psychologists. These measures helped to improve the quality of parents-specialist interaction and rehabilitation outcomes.

Relevance for users and families:

Parents dissatisfaction towards the pediatric rehabilitation services are most often mentioning structural elements and process elements. To ensure parents' satisfaction and prevent dissatisfaction, managers and service providers should stress the importance of Family-Centered Care (FCC) and the implementation of the biopsychosocial approach both to the specialists and family members which will reduce waiting lists, provide respectful and supportive care, and ensure services are coordinated across locations and over time.

Early Detection of Childhood Autism Spectrum Disorder in the Malaysia: Validity and Reliability of the Malay Translated Version of the Modified Checklist for Autism in Toddlers, Revised with Follow-up (M-CHAT-R/F)

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Introduction: Autism Spectrum Disorder (ASD) is a neurodevelopmental disorder with social communication impairments and specific restricted, repetitive behaviours. The prevalence of ASD has increased significantly in the past few decades and it has a marked impact on affected children, their families and society. M-CHAT-R/F is recognized as a valid and reliable tool for ASD screening. To utilize this tool effectively, having a translated version in the local language is imperative. In this study we translated M-CHAT-R/F to the Malay language and performed reliability and validation studies on the translated version.

Patients and Methods: 244 children aged 16-30 months were recruited from Universiti Kebangsaan Malaysia Medical Centre between Dec 2019 to August 2022. M-CHAT-R/F was translated to Malay and internal reliability and validity of the Malay version was assessed.

Results: The Malay M-CHAT-R/F had good face validity and internal consistency. The validity of the M-CHAT-R/F Malay version was tested against the original using the t-test, which showed no difference between the two versions [Malay: 11.90 (SD 4.71) vs English: 12.05 (SD 4.92), t=-0.10, p =0.924). The reliability of Malay M-CHAT-R/F was tested using parallel-form reliability and it was strongly correlated with the English-version ($r = 0.975$, $p < 0.001$). Assessment of the Malay M-CHAT-R/F showed sensitivity of 83.3% and specificity of 79.2%, with positive predictive value 70.1% and negative predictive value 89.1%.

Conclusion: The Malay version of the M-CHAT-R/F is a reliable and valid tool to screen for ASD in children. Early screening is crucial to institute effective early intervention.

Relevance for users and families:

ASD is increasing in prevalence and can affect families significantly. It is imperative to detect this condition early as early intervention can have a consequential impact on the outcome in these children. By using a reliable tool in the local language, families of children with ASD can access intervention earlier, with potential of better outcomes. Positive outcomes will enable children to reach their full potential and reduce burden of disability on their families.

An 8-year young boy with cerebral palsy co managed with a physical therapist.

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Introduction and complaints: An 8 year young boy RC was referred to us by a physical therapist for visual evaluation and management. RC had hypoxic insult during birth and had suffered from hypoxic ischaemic encephalopathy.

Evaluation: He could stand with support and walk a few steps holding the table. RC would hold his head tightly in one position while visually fixating at some object. He would try to hold his legs apart with the feet turned inwards. His ocular movements were not smooth, and he was trying to restrict them. He had 12 prisms exophoria for near and almost 10 prisms exophoria for distance. NPC was receded and MEM showed a lead of accommodation. NSUCO was performed in the seated position and his scores were very poor with inaccurate and rugged pursuits as well as saccades

Therapy plan: RC had poor spatial orientation, poor visual motor coordination, high and posteriorly shifted centre of gravity, ocular movement disorder and high exophoria. We provided RC yoked prisms during therapy and worked with large peripheral vectograms, Brock string at distance and Hart chart activities. RC was prescribed a small binocular plus with binasal occlusion.

Initial outcome: After 45 sessions, RC was able to stand independently for about 10 minutes while looking around. He was able to take a few steps independently too. However, that was not very consistent. RC's phorias were 4 and 6 prisms exo for distance and near respectively. NSUCO scores were much better with reduced head and body movements.

Relevance for users and families:

Importance of involving vision to achieve better physical therapy Results.

More than Motor: Case series exploring language, cognitive and social development in Spinal Muscular Atrophy, Type I

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Introduction: Spinal muscular atrophy is a genetic progressive neuromuscular condition characterised by progressive weakness of skeletal and respiratory muscles. SMA has a range of severity which varies according to age at onset of symptoms and motor function achieved and is classified into subtypes SMA I (most severe) to SMA IV (least severe). Research exploring development in SMA, including clinical trials of treatments, has centered on survival rate and motor outcomes. Literature on cognitive performance in SMA is limited (Polido et al 2019), lower cognitive outcomes were noted in more recent studies and those which included children with SMA I.

Patients and Methods: We present a case series of 3 consecutive patients with SMA I who underwent developmental assessment at 18, 24, 30, and 36 months as part of multidisciplinary service provision with a paediatric neurodisability service. Assessment included Bayley's Scale of Infant Development Third edition, Social Communication Questionnaire; Child Behaviour Checklist; Vineland Adaptive Behaviour Scales, Third edition.

Results: Across 4 time points, all 3 patients demonstrated higher scores in cognitive development and receptive language development and lower scores in expressive language development. Two patients demonstrated cognitive development in the average range and one patient demonstrated below average cognitive development and high ratings of social communication difficulties.

Conclusion: This case series provides evidence of a spectrum of cognitive, language and social development outcomes in children with SMA I. This reinforces the value of including multidisciplinary developmental assessment as part of the service provision for children with SMA.

Relevance for users and families:

Neuromuscular clinic appointments and treatment assessments focus on motor skills. The parents of children with SMA I that we work with tell our team that they want us to also look at their child's communication and thinking skills. They say this is information they need to help them to understand their child, to decide on educational placements. This work tells us that assessments including psychology and speech and language therapy benefit children with SMA I.

Identifying childhood apraxia of speech in younger children and children with severely impaired speech using Dynamic Evaluation of Motor Speech Skill

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Introduction: Childhood apraxia of speech (CAS) is a neurological speech disorder affecting accuracy and consistency of oral movements required for speech. There is a consensus on the key factors defining CAS: disrupted coarticulatory transitions between sounds, variability and inconsistency in word repetition and disordered prosody.

Test materials and assessment protocol were developed for assessing speech in younger children and children with little speech. We assessed the feasibility of identifying key factors of CAS with Dynamic Evaluation of Motor Speech Skill (DEMSS).

Patients and Methods: The sample included 25 children, 16 boys, between 3.5 and 7 years with severely impaired speech. Hearing disorders, oral anatomical anomalies and neurological disorders that could affect speech production were excluded.

DEMSS was used to assess the children's speech based on the criteria to identify CAS. All key features were assessed, including coarticulation in words, speech variability and prosody.

Results: The data show that DEMSS accurately identified and differentiated between children with CAS, phonological disorders and children who showed some signs of CAS with significant phonological disorders. Key features of CAS were identified in more than half of the children. A test-retest reliability was conducted over a short period.

Conclusion: Early identification is critical for effective and targeted therapy of children with CAS. Dynamic evaluation using a list of syllables, words, and phrases has been shown to be an appropriate tool for identifying children with CAS as well as for differentiating motor disorders from phonological disorders in younger children and children with little speech.

Relevance for users and families:

Identification of CAS is critical for providing early intervention and for choosing the appropriate therapeutic intervention. A well-planned intervention is necessary for a better outcome and has a positive impact on the child's overall development.

Single centre audit of lower limb Orthopaedic interventions for children with cerebral palsy

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Introduction: Children with Cerebral Palsy (CP) often present with muscle tightness and contracture, joint deformity, spasticity, and pain. Orthopaedic management of these impairments includes orthopaedic surgery, Botulinum Toxin and steroid injection. The aim of this retrospective review was to examine recommended interventions in a single centre over two time-periods. A secondary aim was to compare interventions across GMFCS levels and orthopaedic surgeons.

Materials and Methods: Relevant data were collated from our centre's electronic databases. Inclusion criteria were a diagnosis of CP (GMFCS I-V), aged 18 years or under and seen within two time periods- 2014 to 2016 and 2019 to 2021.

Results: A total of 1,463 valid records were reviewed (GMFCS level I 33%, II 15%, III 11%, IV 23%, V 18%). The percentage of those recommended for each intervention or no intervention during each time period were as follows- Botulinum Toxin (29%; 18%), surgery (11%; 8%) steroid injection (2%; 6%) and no intervention recommended (57%, 68%). These differed both across GMFCS levels and between surgeons.

Conclusions: While Botulinum Toxin injection was the most popular intervention, the rate of injection has reduced over time while the percentage of those reviewed and no intervention recommended increased. Surgery rates remained relatively stable over time. While clinical decision making, and family preference were not considered in this study, the Results highlight the importance of regular service audit and review against established best practice.

Relevance for users and families:

Relevance for users and families: This data can be used to plan resources and expectations around likely interventions in CP.

Decline in frequency and severity of cerebral palsy in South Australia 1993-2016

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Introduction: To describe the change in severity of cerebral palsy in South Australia between 1993-2016.

Methods: All consented cases on the state register (n=738), following an clinical assessment at age 5 years, were classified according to gross and fine motor skills (using Gross Motor Function Classification System and Manual Ability Classification System) and intelligence. To assess change over time, Poisson regression was performed for categories of mild and moderate/severe disability, in addition to GMFCS and MACS.

Results: There was a general trend for reductions in the number of cases for every subsequent year in both mild (β=-0.023, p<0.001) and moderate-severe disability (β=-0.034, p<0.001). GMFCS analysis demonstrated that the number of cases reduced by 1 case per year for both GMFCS I (β=-0.05, p<0.001) and GMFCS V (β=-0.05, p=0.003). Conversely, cases at GMFCS II-IV showed a non-significant increase of one case per year per group. Manual function demonstrated a general reduction in both mild (MACS 1-2; β=-0.063, p=0.002) and moderate/severe (MACS 3-5; β=-0.123, p<0.001) disability by case count per year. There was a general reduction in both normal intelligence (β=-0.025, p<.001) and intellectual disability (β=-0.48, p<0.001) with the number of children in both groups reducing by approximately 1 child per year.

Conclusion: The findings confirm a sustained reduction in the prevalence of cerebral palsy by overall severity of disability, and a stepwise trend of reduction in motor and intellectual disability. The reduction in GMFCS level 5, with increases in levels 2-4, suggest a trend in reduction in motor impairment over time.

Relevance for users and families:

This study highlights a continuing reduction in the number of new cases of cerebral palsy listed on this state-based register in Australia, and overall reduction in the severity of the condition when assessed at five years of age.

Healthy Parent Carers programme: peer-led group-based intervention to improve health and wellbeing of parents of disabled children

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Statement of problem: Primary carers of disabled children face increased risks of mental and physical health problems. They prioritise the needs of their children often to the detriment of their own health. They report that generic health promotion programmes fail to take account of the unique difficulties that parent carers face.

Description of the product or technology: Healthy Parent Carers aims to improve health and wellbeing by promoting behaviours associated with better health – Connect, Learn, be Active, take Notice, Give, Eat well, Relax, Sleep (CLANGERS). The logic model predicts that engagement with CLANGERS improves resilience and overall health and wellbeing. The programme facilitates behaviour change by providing opportunities for, and prompting, social (peer) support, development of a shared social identity, sharing of experiences, and the practice of health-related behaviours. This is achieved through (i) facilitated group-based activities and discussions, and (ii) providing health-related information and resources. The 12 modules are delivered in person or online by two trained peer facilitators.

Findings to date: We have demonstrated feasibility of in person online training and delivery, acceptability to participants, affordability to delivery-partner organisations. WE continue to evaluate aspects of accessibility and equity. Participant surveys and qualitative research describe how the programme has enabled them to make positive changes to their health and wellbeing. Online delivery has increased the reach of the programme and reduced costs.

Practical applications: Healthy Parent Carers has been implemented successfully in collaboration with charities, Local Authorities and NHS commissioning groups in multiple settings in the UK.

Relevance for users and families:

Only peer-led group-based intervention solely designed to improve the health of parent carers, co-created by parents of disabled children for parents of disabled children

Physical activity in adolescents with autism spectrum disorder: current state of the literature

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Being physically active is crucial for developing and maintaining good physical and mental health. Numerous meta-analyses indeed illustrate the independent and beneficial effects of physical activity on physical health and mental wellbeing in children and adolescents.

However, evidence-based research shows that adolescents with autism spectrum disorder (ASD) are significantly less physically active compared to their typically developing peers, making them more vulnerable to develop an inactive lifestyle and consequently poor health outcomes. As a result, it is important to target this at-risk population.

During this oral presentation, the current state of the qualitative and quantitative literature on physical activity in adolescents with ASD will be outlined. The focus will be on the assessment, levels, interventions, correlates, barriers and facilitators of physical activity in adolescents with ASD. Recommendations for clinicians, as well as for future research will also be provided.

Relevance for users and families:

This oral presentation will inform researchers, clinicians, people with lived experience, their family members and close others concerning the importance and evidence-based research of physical activity in adolescents with ASD.

"The Inclusion of Students of Refugee Origin in a Special Education School Unit: An Early Intervention Case Study"

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In the climate of modern developments and the increase in refugee inflows in countries, the field of special education seems to be expanding. The difficulties of integration of children of refugee origin, in the Greek educational context, increases when there is a coexistence of disability and/or special educational need. Special education school units, due to their multidimensional staffing of educational and special education staff (psychologists, social workers, nurses, occupational therapists and physical therapists), are called upon to welcome these children, not only as a place of special education but also as an inclusive environment.

The aim of this qualitative study was to investigate the integration processes of three students of refugee origin in a school unit of special education. More specifically, the aim was to investigate the ways in which categories and social locations such as gender, race, disability, social class, intersect, interact and overlap, influencing the formation of programs and actions aimed at the inclusion of these children.

The empirical material was gathered through interviews with the staff of the school unit. Based on the thematic analysis of the collected material, it appears that inclusion is a meaningful process and the goals, course and evaluations vary among its participants. The area of special education is not a one-way environment of isolation and segregation, but can be an open field where diversity and respect for "others" can be objects of negotiation and redefinition.

Relevance for users and families:

Family Support and strengthening of Children's self-efficacy/self-motivation challenges the firmness of the distinction between special and general education.

The area of special education may not be a one-way towards isolation and segregation, but it may also be an open field where inclusion and diversity can be negotiated and reinterpreted.

Impact on quality of life: Providence nighttime brace versus traditional full-time orthosis

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Introduction: Standard treatment for skeletally immature adolescents with moderate Adolescent Idiopathic Scoliosis (AIS) is a full-time spinal orthosis. However, adherence to full-time wear is often challenging for these patients. The impact on the quality of life (QOL) of patients and their families is enormous. Providence nighttime bracing is a good alternative in these patients.

Patients and Methods: We have analyzed the impact on QOL of Providence nighttime brace and traditional full-time orthosis in a prospective cohort study comparing 40 patients with AIS: 20 treated with Providence nighttime bracing and 20 with traditional full-time orthosis. Scoliosis Research Society (SRS) bracing criteria were included to prescribe it. For each patient a personal orthosis was created depending of the characteristics of the curve. The QOL was analyzed with PedsQL (Pediatric Quality of Life Inventory TM). The tests were carried out on both patients and parents three months after starting the treatment.

Results: Both groups are epidemiologically and pathologically similar. X-ray curve control is good in both groups. In the Providence group we see higher levels of QOL as measured by PedsQl, scoring higher in both patients and families. Patients score higher in both groups than families.

Conclusion: The Providence nighttime brace is an effective treatment for patients with moderate (T/TL) AIS. In addition, it reduces the impact on the QOL of both patients and families.

Relevance for users and families:

In dealing with AIS, full-time orthosis mean an important lifestyle change. Nigghttime brace could be an important tool to reduce psychological burden and increase self-esteem.

Stakeholder-informed strategies to facilitate participation in circus-based recreational physical activity for preschool-aged children born preterm, a mixed-Methods study.

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Introduction: Preschool-aged children born preterm participate in less physical activity (PA) than term-born children. They may also experience increased risk in multiple health domains and therefore engaging in adequate physical activity to capitalise on the physical, social and cognitive benefits may be even more essential for this cohort. Circus activities (a type of recreational PA) is a potential avenue to increase PA rates, but further insight into how to tailor these to address the participation gap is needed. This study investigated barriers and facilitators informing participation in recreational PA for preschool-aged children born extremely preterm (EP) and explored strategies to enhance participation in circus activities.

Patients and Methods: A sequential mixed-Methods study utilising surveys (n=217), interviews (n=43), and a focus group (n=6) was undertaken with key stakeholder groups (parents of children born EP, coaches, and clinicians). Qualitative data (Framework Method) and quantitative data (descriptive statistics) were mixed during preliminary and final analyses.

Results: Five themes were developed from the mixed data: the crucial role of the coach and the need for specific training, the therapeutic role of PA and promoting outcomes beyond the physical, the impact of communication and class planning, consideration of convenience and cost, and finally, the guiding role of clinicians.

Conclusion: Barriers, facilitators, and proposed strategies were identified which may be used to modify or co-design circus-based PA interventions to enhance participation and improve rates of PA for preschool-aged children born preterm. Targeting the preschool age is essential to promote development of fundamental motor and social skills.

Relevance for users and families:

Designing timely opportunities for physical activity that is responsive to the needs identified by families is a crucial step in improving participation. Clinicians can use these findings to inform referrals for this cohort to recreational physical activities, while providers of programs for this age can take steps to modify their classes to be more inclusive to children born preterm and their families.

CirqAll: preschool circus for premmies, a novel co-designed physical activity intervention for preschool children born preterm.

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Introduction: Preschool-aged children born preterm participate in less physical activity (PA) than term-born children. Supporting PA at the preschool age may include participation in recreational PA, such as circus activities. Circus is uniquely positioned for use as a participation intervention due to its huge variety, uniqueness, and naturalistic leisure setting, with demonstrated improvements in physical and social-emotional outcomes for varied paediatric populations. Involving families and other relevant stakeholders in intervention design is advocated for on pragmatic and moral grounds. Therefore, this study aimed to co-design a circus-based intervention to increase PA participation for preschool-aged children born preterm and undertake feasibility testing of part of the resulting intervention.

Methods: Parents of children born preterm (n=4), clinicians (n=2), coaches (n=2), and clinician-researchers (n=2) attended eight 90-minute meetings to co-design the intervention: "CirqAll: preschool circus for premmies". CirqAll has three components: (1) specialised coach training, (2) separate introductory classes for preterm children only, (3) ongoing integrated classes. Feasibility testing of Component 1 evaluated recruitment capability, acceptability, and implementation fidelity, with analysis via descriptive statistics.

Results: Feasibility of Component 1 showed good recruitment capability (51 coaches enrolled in 8-weeks); good retention (>80% retained); high acceptability (>90% of respondents rated intervention as acceptable); and moderate fidelity (44% of participants completed >50% of the intervention, Zoom workshops adhered to >90% of plan and 100% of respondents indicated satisfaction with the workshops).

Conclusion: CirqAll is a co-designed intervention which aims to enhance PA participation for preschool-aged children born preterm. Feasibility testing of Component 1 shows promising Results.

Relevance for users and families:

Families' unique perspectives on constructs such as barriers, facilitators, and outcomes are essential in the design of health interventions, especially when they are the end-users of the service. For participation interventions this is crucial as exposing children with additional needs and their families to PA in a positive way enables them to experience enjoyment and success early so that they have the best chance of continuing to engage in, and benefit from, PA.

Looking toward a 24-hour activity approach: A feasibility study on the effect of locomotor training and task specific practice on sleep in pre-school aged children with neurodevelopmental disorders.

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Introduction: Sleep is important for health and well-being, yet the effect of activity interventions on sleep in children with neurodevelopmental disorders (NDD) have not been extensively explored. We aimed to determine the potential effects of a pre-school aged locomotor training and task specific program on sleep.

Patient and Method: Forty-two children with NDD (mean 3.4y, SD 1y; GMFCS (or equivalent) levels II to V) participated in a locomotor training program (3, 2-hour sessions/week over 4 weeks). Co-morbidities included epilepsy (n=29), vision impairment (n=9) and hearing impairment (n=5). Caregivers completed the Sleep Disturbance Scale for Children (SDSC, pre-school version) at the start of the program (TP1), at the end of the program (TP2) and at 4-weeks follow-up (TP3). 'Pathological' scores were indicated by a T-score > 70. Linear mixed models were used to compare within group differences.

Results: There were significantly reduced ($p<0.05$) SDSC T-scores for both the total score and in the domain of Difficulty Initiating and Maintaining Sleep (DIMS) at TP2 vs TP1 as well as at TP3 vs TP1.

Conclusion: The improvement in scores over time in both total and DIMS scores suggests that daytime physical activity and engagement may influence getting to and staying asleep. Future studies should focus on influencing mechanisms and wearable technologies to record accurate sleep-wake events over a 24-hour period.

Relevance for users and families:

Relevance for Users and Families: Engaging in daytime activities may influence sleep even in children with multiple co-morbidities. Engagement in daytime activities should be considered within the 24-hour activity approach.

Performance of everyday activities in persons with cerebral palsy – a complex process that needs to be understood

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Introduction: The performance of an activity can be seen as a complex process consisting of different phases (generate idea, plan, initiate, enact, adjust, end) and time management. This has been described at a general level in the Model of the Process of Doing (MPoD). There is a knowledge gap about how persons with cerebral palsy (CP) experience their 'process of doing' while performing everyday activities. Therefore, the purpose of this study was to describe how young adults with CP, MACS-level I-II, perceive challenges in their performance of daily activities in relation to the phases of the 'process of doing'.

Participants and Methods: Qualitative face to face semi-structure interviews were held with 10 young adults with CP, 19-30 years old. Deductive analysis of the semi-structured interviews was caried out using directed content analysis. The frame of reference for the analysis was MPoD.

Results: The participants' descriptions of how they perceived their 'process of doing' showed problems in all phases of the MPoD. All participants reported difficulties in one or more phases, but none experienced difficulties in all phases.

Conclusion: To fully understand the complexity of doing everyday activities in persons with CP, there is a need to address all phases of the 'process of doing', as well as the interplay between the person, the activity, and the environment. This will broaden the scope of suitable intervention Methods for persons with CP.

Relevance for users and families:

By addressing all phases of the process of doing the person gains an understanding of the causes of difficulties in performing the activity and professionals can choose an intervention that addresses the actual problem. The right intervention at the right time increases the chances for the person to develop self-efficacy.

Behavioral, social and emotional difficulties and health-related quality of life among five-year-old children born very preterm: Results from a European cohort

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Introduction: Behavioral, social, and emotional difficulties (BSED) among children born very preterm (VPT; <32 weeks' gestation) are an important concern. We aimed to determine the prevalence and factors associated with BSED at five years among VPT-born children and to analyse the association between BSED and health-related quality of life (HRQoL).

Patients and Method: Children born VPT in 2011-12 in 11 European countries were included in the analysis (n=3,501). Family characteristics and child health information were collected using parental-report questionnaires, including the Strengths and Difficulties Questionnaire (SDQ) to assess BSED and the Pediatric Quality of Life InventoryTM to measure HRQoL. Logistic regressions unadjusted and adjusted for country were performed to analyse factors associated with BSED (defined as SDQ total difficulties score ≥80 percentile using UK test norms).

Results: 23.3% of children born VPT had BSED, ranging from 13.1% in the Netherlands to 36.0% in Poland. BSED were associated with younger maternal age [<25 years; OR; 95% CI = 1.47; 1.13–1.91], low maternal education [2.19; 1.73–2.78], having a foreign-born mother [1.38; 1.10–1.73], at least one parent unemployed [2.82; 1.42–5.60], male sex [1.50; 1.27–1.75], birth <28 weeks' gestation [1.67; 1.41–1.99], congenital anomalies [1.50; 1.14–1.96], bronchopulmonary dysplasia [1.79; 1.43–2.24] and severe neonatal morbidity [1.84; 1.44–2.34]. HRQoL decreased with increasing BSED.

Conclusion and Relevance for users and families: Screening for BSED in early childhood may identify children at greatest risk for whom early intervention may be warranted.

Relevance for users and families:

Screening for BSED in early childhood may identify children at greatest risk for whom early intervention may be warranted.

Quality of life and participation in activities of daily living in children with cerebral palsy

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Introduction: There is not much information on association between Quality of life (QoL) and participation in children with cerebral palsy (CP).

Aim: We wanted to explore the associations between Gross Motor Function Classification System levels (GMFCS) and QoL in CP children.

Methods: 30 children (20 boys) with CP (mean age 8,5 years) were included in a pilot study. Data on GMFCS level, QoL (Quality of Life Questionnaire for Children) and participation (Paediatric activity card sorts, PACS) were collected and analysed.

Results: The QoL was scored high by either children or their parents, with highest mean scores in Emotional wellbeing and self-esteem subscale, followed by Social wellbeing and acceptance, Feelings about functioning, Participation and physical health, Family Health, Access to Services (from 89,4% to 72%). The lowest scores were reported in Pain and impact of disability subscale (17,7%). Reported participation ranged from 73% (personal care), 72% (hobbies), 57% (school/productivity) to 37% (sports), with obvious trend toward lower participation in all categories of activities for children in GMFCS levels 4 and 5, who also reported on lower QoL. Children in GMFCS levels 1 and 2, reported on higher scores for participation in category of activities of personal care (82%) and hobbies/social activities (75%), but lower scores in category Participation and physical health (78%).

Conclusion: Participation and QoL in children with CP are not straightforwardly interconnected, depending on GMFCS level, but also on other variables, that should be analysed. Assessment of QoL and participation should be mandatory components in goal planning in rehabilitation.

Relevance for users and families:

In the process of rehabilitation, it is important to measure and monitor not only the functional state of the child, but also his participation in activities of daily living and guide therapy based on this. It is especially important to assess participation of young children as their function at this age may predict their educational and social integration in later years. Participation predicts quality of life and has impact on health and motivation.

A scoping review of mental health conditions and interventions among adults with cerebral palsy

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Introduction:Although Cerebral Palsy (CP) is diagnosed in childhood and non-progressive, it is a lifelong condition. Adults with CP have significantly higher odds of developing chronic diseases. Mental health is also a growing concern. This review examined the prevalence of mental health conditions and targeted mental health interventions among adults with CP.

Patients and Methods:EMBASE, Ovid MEDLINE, Global Health, APA PsycInfo, Web of Science and Cochrane Library databases were searched from inception to July 2022. Studies that included measures of mental health prevalence, shared experiences of mental health and targeted interventions among adults (>16 years) with CP were included.

Results:Of the 8,416 studies imported for screening, 172 full-texts were assessed for eligibility. Twenty-five of these met the inclusion criteria. The majority of studies (80%) examined the prevalence of mental health conditions, with pain levels contributing to increased levels of anxiety and depression. Only 3 studies examined interventions to support mental health (mindfulness, CBT and lifestyle), while a further 2 studies captured lived experiences of mental health. Most studies were limited to young adults with CP (<30 years).

Conclusion:Studies examining mental health among people with CP is very limited. Despite the worrying prevalence of mental health conditions among adults with CP there is a dearth of evidence-based interventions. Mixed-Methods research is warranted in larger sample sizes of older adults with CP.

Relevance for users and families:

This review demonstrates the urgent need to incorporate mental health screening into routine clinical care for adults with CP. These Results could also aid the development of interventions to support mental health for those living with CP.

When experts by theory work together with experts by experience: lessons learned from partnering with individuals with cerebral palsy in a research project

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Introduction: Public and Patient Involvement in research (PPI) is a rich approach to enhance research relevance. Here we aim to share researchers' and patients' experiences on the process of PPI in the development of a questionnaire to assess the transition to adulthood of individuals with cerebral palsy (CP).

Patients and Methods: 16 adolescents and young adults with CP (AYACP), 13 to 30 years old, GMFCS-self report level I-IV, with preserved cognition, varied educational and socioeconomic levels from all regions of Brazil are partners in this research. Open-ended questions and discussions were used to collect AYACP experiences. The Involvement Matrix was used to manage their involvement. The data were analyzed qualitatively.

Results: The questionnaire development took 1 year to be completed, twice the time expected. Just 3 AYACP dropped out. Researchers needs to adapt data collection according to the public available time, and night and weekend may are the most suitable moments for the public to engage. Since recruitment, AYACP had shown great interest in being involved in research. Along the study, AYACP gained confidence to spontaneously increase their level of involvement. Several specific questions about transition to adulthood were raised by them, showing the complexity and the need for a broader view during research and practice.

Conclusion: PPI has low cost and great impact. When adopting PPI, researchers should keep in mind that flexibility and building a relationship of trust and partnership is key. Specific needs can be better understood when partnering with the public, thus PPI should be encouraged.

Relevance for users and families:

The partnership with experts by experience (AYACP) in research can give to the experts by theory (Researchers) a deeper understanding of some issues that urge to be addressed and possibly could be ignored. AYACP want to partner with the researchers, feeling valued by having their knowledge recognized. The involviment of AYACP has given them more self-confidence that, according to them, resonates in their personal lives beyond research.

The quality of life of children with disabilities in Romania: Results from a parent report survey.

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Introduction: The health-related quality of life (QoL) of children with chronic illnesses in developed countries is lower than the QoL of their healthy peers. For example, children with chronic conditions in California scored 71.89 on the Paediatric Quality of Life Inventory (PedsQL), while their healthy peers scored 81.95. To our knowledge, no studies have yet reported on the QoL of children with disabilities in Romania. This study therefore aims to describe the QoL of children with disabilities in Romania.

Patients and Methods: Parents/primary carers of children aged 2-16 with a disability in Romania completed an online survey which included the PedsQL 4.0, measuring their child's health-related QoL on a scale of 0-100. Participants were recruited through partner organisations/charities which provide support services to children with disabilities in Romania.

Results: Survey data from 88 participants who completed the survey during October-November 2022 show that QoL of children with disabilities in Romania is impacted in all domains, scoring an average of 55.74 in physical functioning, 44.92 in psychosocial functioning and 48.70 in the total functioning scale.

Conclusion: Early survey Results show that children with disabilities in Romania have a significantly lower QoL than their peers with chronic illnesses in developed countries.

Relevance for users and families:

This study suggests there is a critical need for intervention. The study has the potential to inform future interventions to improve QoL for children with disabilities and their families in Romania.

Early Signs and Characteristics of Functioning and Contextual Factors at an Early Age in Children at High-Risk or with Developmental Coordination Disorder.

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Introduction. Developmental coordination disorder (DCD) can significantly impact body structures and functions, activities, participation, and contextual factors. Identification of early signs in functioning and daily life activities seems to play an essential role, with DCD being considered one of the disorders whose repercussions can affect them more directly. Although the limitations it causes are well documented as of the age of 6, before that age, there are already some skills that parents refer to as difficult. Using a scoping review methodology, we aimed to identify the characteristics or signs that can have an early impact on the development and functioning of children with DCD between 0 and 6 years.

Patients and Methods. This study presents a list of specific characteristics of functioning and participation in children at high risk or diagnosed with DCD between 0 and 6 years of age, extracted from the analysis of the Results of the articles included in a scoping review.

Results. Thirty-two different signs and characteristics of functioning and contextual factors were referred to as being more difficult by the primary caregivers in 11 of the 17 articles included in the scoping review. They were grouped into five areas: general, meals, grooming, manual activities, games and leisure, and dressing.

Conclusion. Early detection of these signs could allow the initiation of systematic and specific processes of evaluation and intervention in children with DCD, which would impact the restrictions on their participation and family well-being.

Relevance for users and families:

By identifying the most common signs and characteristics at an early age, this review offers a framework on which families, and also other primary caregivers, and health, educational and social professionals, could base their observations when detecting difficulties.

Enhancing participation of youth and young adults with physical disabilities via the PREP intervention: Experiences of young people and their therapists

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Introduction: Youth with physical disabilities face participation restriction, which is further exacerbated by the pandemic. Environmental-based participation interventions, such as the Pathways and Resources for Engagement and Participation (PREP), are effective at improving youth participation; yet their impact during adverse times is unknown. This study, therefore, aimed to elicit the experiences of PREP intervention among youth with physical disabilities and therapists in Quebec, Canada during the COVID-19 pandemic.

Patients and Methods: Youth (n=13) aged 18 to 25 (median=21) that participated in an 8-week self-chosen activity (football, piano, photography), facilitated by the PREP, and therapists (n=6) that delivered the PREP, took part in an individual semi-structured interview in English and French. Thematic analysis was conducted by two researchers independently and common themes were identified.

Results: Five common themes emerged from both the youth and the therapists: 1) Seeking resources and putting them together; 2) Navigating multiple barriers during the pandemic; 3) Support from family members and connections with instructors as assets; 4) Not only fun but also a new opportunity to experience changes; and 5) Positive reception of the intervention. Findings, based on youths' positive experiences, indicate that the youth discovered the value of trying new activities in supportive and accessible environments.

Conclusions: Youth with physical disabilities had positive experiences in activities that aligned with their interests despite additional barriers and challenges brought on by the pandemic. This study highlights the crucial roles of therapists, families, and instructors in mobilizing available resources and keeping youth's motivations to enhance their community participation.

Relevance for users and families:

Results highlight the importance of participation-based interventions with dedicated therapist time for both youth and families. It demonstrates the importance of directing these interventions towards leisure activities that align with youth's interests ensuring a more positive experience and greater motivation even during adverse times. Findings can inform clinicians on the need and benefits of environment-based interventions to facilitate meaningful participation of youth with disabilities in their own community, enabling confidence to improve participation more broadly.

Participation Profile of Children and Youth, Aged 6–14, With and Without Disabilities (ADHD; ASD), and The Impact of Environmental Factors

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Introduction: Children and youth with disabilities (e.g., attention deficit hyperactivity disorder; ADHD, autism spectrum disorder; ASD) may experience difficulties in participation. Therefore, it is necessary to address their participation and the environmental factors that may support or limit it. Two studies aim to explore the participation patterns of children with and without disabilities, in the home, school and community settings, to identify the environmental supports for and barriers against participation and to examine the availability of supporting resources.

Patients and method: Parents of 65 participants aged 6–14 with and without ADHD (1st study), and 78 parents of children aged 6-12, with and without ASD (2nd study), completed the Participation and Environment Measure for Children and Youth questionnaire, along with demographic and screening questionnaires.

Results: Children with disabilities (ADHD; ASD) were rated significantly lower than children without disabilities in frequency of participation, involvement, and overall environmental support, with parents expressing a greater desire to change their child's participation. Among children with disabilities significant differences in participation were found in all settings, and significantly higher in home. Additionally, environmental factors were identified by parents.

Conclusion: The findings demonstrated differences in the participation of children and youth with disabilities across different settings, compared to those without disabilities, and confirmed the effect of environmental factors (e.g., other people's attitudes, relationships with peers, cognitive activity requirements) on participation, especially involvement. It is essential to consider participation measures and environmental factors when designing interventions, in order to improve participation patterns in various activities in different settings.

Relevance for users and families:

It is essential to consider participation measures and environmental factors when designing interventions dor children with disabilities in order to improve their participation patterns in various activities in different settings.

Comorbidities of deformational plagiocephaly in infancy: a scoping review

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Introduction: Deformational Plagiocephaly (DP) is the most common type of cranial asymmetry in infancy that Results from the prenatal or postnatal application of external forces to an infant's occiput whereas the cranial sutures are open and normal and no craniosynostosis is present. The increase in the prevalence of DP is generally attributed to the American Academy of Paediatrics recommendation to put babies to sleep on their backs to avoid the sudden infant death syndrome. DP is characterized by unilateral flattening of the skull and it is often suggested to be associated with comorbidities such as developmental delay. Currently, reports vary on the comorbidities of DP, for instance whether facial deformation, asymmetry in motor behaviour or muscle tone impairments are associated with DP. Therefore, the aim of this scoping review (ScR) was to identify and describe systematically the characteristics of comorbidities occurring in children with DP until the age of two years.

Materials and Methods: The search strategy followed the Population, Concept and Context (PCC) framework according to the recommendations of Joanna Briggs Institute for ScR. Eligible studies were collated and presented in a qualitative analysis.

Results: Twenty six studies met inclusion criteria covering developmental delay, speech production, auditory system, visual field, mandibular structure and neurological issues. Details of the associations will be reported.

Conclusions: The findings of this ScR review may support the clinical decision making and early intervention strategies in regards to DP and relevant comorbidities.

Relevance for users and families:

The Results of this ScR suggest that health professionals should monitor the development of children with DP at least up to the age of two years. Caregivers of infants with DP deserve guidance on how they can optimize their child's developmental outcome.

Rapid Access Clinic for Children and Young People with Severe Neurological Impairment

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Problem: Severe neurological impairment (SNI) describes a 'group of disorders of the central nervous system which arise in childhood, resulting in motor impairment, cognitive impairment and medical complexity, where much assistance is required with activities of daily living' (Allen et al, 2020). These children have high care needs and high healthcare needs. They interact frequently with medical professionals, have high levels of hospitalisations and a significant symptom burden (Feinstein et al, 2020). Children with SNI require timely and specialised intervention for medical problems and early links with a multidisciplinary team (MDT).

Product: A rapid access clinic for children with SNI was recently established. This is a twice-thrice monthly clinic for new referrals with SNI, or children with SNI attending any of the services in our hospital who are unwell, have new pain or symptoms. It is a multidisciplinary clinic attended by psychology, dietitian, clinical nurse specialists and neurodisability consultants depending on the patients' need.

Findings to date: Patients reviewed have had diverse symptomatology including feed intolerance, weight loss, pain, infections e.g. tonsillitis. The clinics have allowed early access to appropriate MDT expertise. We have also reviewed 6 new patients with SNI- many recently immigrated to Ireland due to the Ukrainian crisis. We have been able to link them in with multidisciplinary services and manage their acute medical needs in a timely way.

Applications: A rapid access clinic has the potential to reduce health deteriorations in a vulnerable population and in turn to avoid emergency department attendances and hospital admissions.

Relevance for users and families:

The establishment of this clinic has allowed patients and their carers access timely specialised interventions for new issues without having to wait for routine clinic appointments or attend the emergency department. Parents have been very grateful for the service to date.

Clinical Effectivity of Nutritional Counseling involving Kolkata Development Model [KDM] in families of children with Autism Spectrum Disorder

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Introduction: Children with autism spectrum disorder (ASD) have various nutritional challenges leading to low nutrition, causing them to deteriorate mentally and physically. Nutrition counseling is pivotal for the development of these children.

Patients and Methods: The data was collected from the nutritional counseling reports of 15 children before and after KDM nutritional input. These reports were analyzed to understand the change in parental eating habits and the BMI of the children.

Results: It is seen that due to nutritional counseling provided by physician, nutritionists and psychologists there has been a shift in the parental eating pattern, which has further influenced the eating behavior of the children. In the reports of the initial phase of treatment, it was seen that all the children had cravings for unhealthy foods. The BMI of 10 children fell within the “underweight” category; whereas 5 of them fell under the “overweight” category. Within 2 weeks of treatment, the parental eating habits such as faulty timings of meals, high sugar consumption, and milk feeding to the children were changed and promptly shifted to a healthy diet. Due to the shift, now, all children follow a balanced diet and have achieved the threshold of a healthy BMI within 3 months’ average time.

Conclusions: This study focuses on the vital role of parental eating patterns on the eating behavior of children.

Relevance for users and families:

In cases of unhealthy BMI, children would have impaired development. Especially, children with neurodevelopmental disorders would suffer more in the long run.

The effectiveness of Parent Training (Program of Care or PoC) in management of children with special needs

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Introduction: Meeting the complex requirements of children with special needs, can put families under great stress. The Kolkata Development Model (KDM) successfully manages these children with its effective multidisciplinary treatment. This intervention starts with a comprehensive Parent Training Module, called Program of Care (PoC), which is supported by PACT Study, UK. The 8-day long parent training equips parents with basic skills to facilitate the improvement in their children.

Patients and Methods: The total sample consisted 50 children with symptoms of neurodevelopmental problems, within the age range of 0-18 years (Mean age = 5 years). The parents were asked to fill the Pediatric Symptom Checklist (PSC) during their initial contact, i.e., pre-PoC and once again post-PoC. It may be noted that the children received no treatment during this period of time.

Results: Data analysis showed that 77.8% and 57.6% of children aged below 6 years and above 6 years respectively, met the cut-off of psychosocial difficulties.

There was a significant difference in overall PSC scores between pre-PoC and post-POC (Mean scores pre-PoC= 31.60; post-PoC = 22.67). The correlational analysis suggests that there exists significant negative correlation between age and difference in PSC scores (between pre-PoC and post-PoC) indicating that, the lower the age of child, the greater the improvement. Linear regression analysis found that the age of a child significantly predicts improvement in the child, (indicated in terms of decrease in PSC scores, post-PoC.

Conclusion: The PoC independently plays a significant role in improvement of children with special needs.

Relevance for users and families:

The change in behaviour of the parents and their parenting style led to decrease in misbehaviours in the children and increase in good behaviours. Such a training module is essential for all the parents especially for those children with special needs for facilitating child's improvement. This training safeguards the parents from taking any unnecessary action that might otherwise hamper the child's treatment. The training also brings a positive change in the parental wellbeing.

Randomised controlled trial of a multidomain parent-delivered early intervention (LEAP-CP Learning through Everyday Activities with Parents) for infants at high risk of cerebral palsy in a Low-Middle Income Country

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Objective: Test efficacy of parent-delivered multidomain early intervention (LEAP-CP) on (i) infant development; (ii) caregiver mental health compared to health advice.

Design: Single blind RCT.

Methods: 153 infants aged 12-40 weeks CA at high-risk of CP were recruited (86 males, mean age 7.1±2.7 months CA, GMFCS I=20,II=35,III=15,IV=28,V=48). Families were randomized to LEAP or health advice (HA) over 15 fortnightly home-visits by Community Worker. LEAP included: (i) goal-directed active training; (ii) Learning Games; (iii) parent education. Both groups received feeding, nutrition and health advice. Primary outcome at 18 months C.A. was mobility on PEDI-CAT. Secondary were Peabody-2, Bayley -III (cognition), COPM, and anthropometry. Intention to treat analysis compared groups using mixed linear models, then excluding infants without CP. Secondary analysis stratified by GMFCS.

Results: No baseline differences between LEAP or HA (n=77/76) groups ($p<0.05$). 118 infants completed (77%retention;9deceased,4withdrew). At F/U there were no group differences on primary or secondary outcomes. Modified ITT analysis on n=96 infants (LEAP n=50, HA n=46), found LEAP GMFCS I-II had better scores on PEDI-CAT mobility (MD4.0(95%CI1.4,6.5),p=0.003); and better HINE scores (MD10.1(95%CI4.8,15.3),p=0.002). Length Z scores favoured HA (MD -0.7(95%CI -1.4-0.0),p=0.05). Both groups improved on all outcomes pre-post intervention.

Conclusions: We found no additional effect of LEAP intervention compared to dose-matched peer-delivered health advice for the whole population. LEAP however led to improved motor skills in milder children, consistent with targeted training. Significant improvements were observed on most outcomes for both groups, suggesting that a parent-delivered program in LMIC is beneficial.

Relevance for users and families:

This paper describes an innovative service delivery model for early intervention with peer trainers for low resource settings.

To identify clinical measures of postural control reported for children with Developmental Coordination Disorder (DCD) and examine their psychometric and clinical properties.

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Introduction: Children with DCD have generalised motor deficits, observable as difficulties in fine motor, gross motor. and postural control. While movement and postural control are interdependent, only the psychometric properties of gross motor measures for children with DCD have been investigated in systematic reviews. Accurate and comprehensive assessment is necessary to identify postural control deficits and determine how these link to everyday functional tasks.

Patients and Methods: Databases searched included: PubMed, CINAHL, Embase and SPORTdiscus. Search terms represented: DCD or dyspraxia and postural control or balance. Quality and psychometric evidence were rated using the COnsensus-based Standards for the selection of health Measurement Instruments (COSMIN) checklist.

Results: Searches yielded 604 papers. 153 were included. From these, six measures included a postural control subscale with between 1-8 items: Movement Assessment Battery for Children First (MABC) and Second (MABC-2) editions, Bruininks-Oseretsky Test of Motor

Proficiency First (BOTMP) and Second editions (BOT-2), Peabody Developmental Motor Scales Second Edition (PDMS-2) and the Lower-Quarter Y-Balance Test (YBT).

Psychometric evidence was strongest for the BOT-2 (validity), MABC (reliability) and MABC-2 (responsiveness). The MABC and MABC-2 had the most positive evidence. The BOTMP had limited, negative evidence. At most, two of seven Systems Theory domains of postural control were assessed by a single measure.

Conclusion: Five measures have postural control subscales with evidence to support use with children with DCD. Collectively, these screen three of seven Systems Theory domains. More comprehensive assessment is needed to guide intervention for children with DCD.

Relevance for users and families:

With the optimal measure, clinicians can help children and their families assess progress and guide intervention to achieve a child's goal and allow increased participation in play and school. Improved understanding of the measures available to assess postural control of DCD will help guide clinicians to choose appropriate outcome measures in their practice. No singular tool will be most appropriate for all children and clinicians must be flexible and adaptable to each child they treat.

Independent wheeled mobility for children with cerebral palsy - a population based study

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Introduction: About one third of children with cerebral palsy (CP) use wheelchairs for mobility. Independent mobility strongly influences children's cognitive and social development. Children without independent mobility have less possibilities of active participation in everyday life. The aim of the study was to explore independent wheeled mobility in children with CP relative to their sex, age, CP subtype, levels of gross motor function (GMFCS) and manual abilities (MACS), and furthermore whether age for independent mobility differed between birth cohorts.

Participants and Methods: Cross-sectional data on children's use of wheelchair and their independent mobility, together with selected demographic data and GMFCS and MACS levels, were retrieved from the Norwegian quality and surveillance registry for CP (NorCP). All children in the registry born 2002-2019 were included, and data were analyzed with logistic regression models and Kaplan-Maier survival analysis.

Results: Of 1780 included children, 640 (36%) used a wheelchair. Of these, 284 children used the wheelchair independently, yet only 20% of these were < 7 years of age. Most children with independent wheeled mobility used a powered wheelchair. Poor hand function was negatively associated with independent wheeled mobility. Over the last 20 years, the age for first time registration of independent wheeled mobility decreased.

Conclusion: Powered mobility should be introduced early to promote independent mobility for children with CP with limited or delayed walking ability. Interventions focusing on improved hand function may be important for achieving independent wheeled mobility.

Relevance for users and families:

Early use of powered wheelchairs promotes young children's independent mobility, and influences their development and participation. Since independent steering of a powered wheelchair is closely associated to children's hand function, goal-directed hand training may be important.

Functional and structural changes at the spinal cord level in children with unilateral cerebral palsy (UCP) after HABIT-ILE : a RCT protocol

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Introduction: Intensive motor-learning-based interventions, including Hand-arm Bimanual Intensive Therapy Including Lower Extremities (HABIT-ILE), have been widely demonstrated to improve motor skills and functional abilities but also to induce neuroplastic changes in children with cerebral palsy (CP). However, the impact of this therapy at the spinal level has never been investigated. The aim of this study is to evaluate the effect of HABIT-ILE on the spinal motor output assessed by mapping the electromyographic activity (EMG) of the motoneuron pools in the spinal cord and by means of factor analysis of the muscle activity profiles.

Patients and Methods: 24 children with UCP (6-18 years) will be randomly attributed to two groups: a treatment group participating in 65 hours HABIT-ILE intervention and a control group (waiting list). All children will be tested with an EMG during a 6-minute Walk Test (6MWT) either before and after therapy (treatment group) or twice without intensive treatment in between (control group). Both groups will be assessed after 3 months follow-up. Bilateral EMG activity from upper and lower limb muscles will be recorded and analyzed to map changes in the spinal cord. In addition, secondary motor functions outcomes will be used to assess potential correlations.

Results and relevance: Functional and structural changes are expected in the spinal cord after therapy as has already been shown in post-stroke patients . Exploring neural changes in response to training, especially in developing nervous systems, is warranted to evaluate and develop successful strategies for early interventions.

Relevance for users and families:

Functional and structural changes are expected in the spinal cord after therapy as has already been shown in post-stroke patients . Exploring neural changes in response to training, especially in developing nervous systems, is warranted to evaluate and develop successful strategies for early interventions.

Intensive Neurophysiological Rehabilitation System for Children with Cerebral Palsy: a Quasi-Randomized Controlled Trial

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Introduction: Recent research demonstrates intensive approaches can be beneficial in children with cerebral palsy (CP). Intensive Neurophysiological Rehabilitation System (INRS) is a multi-component approach that addresses functional goals. The study aimed to examine the INRS treatment's effectiveness in children with bilateral CP.

Patients and Methods: 48 children with spastic bilateral CP (age 5-12 years, GMFCS Levels I-IV, MACS Levels I-IV) participated in this quasi-randomized controlled study. The experimental group underwent INRS treatment and continued routine home treatment for four weeks. The control group, after the first evaluation, stayed on the waiting list for four weeks receiving home treatment and then came for INRS treatment. All participants were assessed three times. Outcome measures included Gross Motor Function Measure 66 Item Set (GMFM), Jebsen-Taylor Hand Function test (JTHFT), Box and Blocks test (BBT), ABILHAND-Kids Questionnaire, Self-care and Mobility domain of PEDI Inventory, and the ankle dorsiflexion passive range of motion.

Results: Repeated measurements ANOVA revealed a statistically significant increase in the GMFM score after the INRS treatment in both the experimental (mean difference (MD) 2.0 points, $P<0.01$) and control group (MD 1.5, $P<0.05$), with a large size effect ($\eta 2=0.21$ and $\eta 2=0.14$). The between-group difference during the first study period reported an MD of 2.89 points ($p<0.01$) in the GMFM score with a medium effect ($\eta 2=0.12$). JTHFT and BBT also obtained statistically significant superiority of the INRS treatment over routine home care.

Conclusion: Study indicates that INRS treatment is effective for improving gross motor functions and hand function in children with bilateral CP.

Relevance for users and families:

This study contributes to the understanding of how intensive motor training affects gross and fine motor function in children with spastic bilateral CP. More experimental research with a clear description of the components of the intervention, its dosage, and timing will help establish future guidelines for intensive rehabilitation that can be used by families, clinicians, and researchers in the field of CP.

Intensive physical training is feasible and effective in children with Heritable Connective Tissue Disorders (HCTD) : a pilot intervention study

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Introduction: Children with heritable connective tissue disorders (HCTD) show reduced physical functioning and could benefit from physical training to improve. However, research on the effect of exercise training in children with HCTD is lacking.

Methods: Ten children with HCTD (Marfan Syndrome n=7, Ehlers Danlos Syndrome n=2, and Loeys Dietz syndrome n=1) participated with consent of the pediatric cardiologist. Physical functioning in terms of aerobic capacity; Fitkids Treadmill Test (FTT), anaerobic capacity; Muscle Power Sprint Test (MPST), and strength and agility; domain strength and agility of the Bruininsk-Oseretsky Test of Motor Proficiency-2 (BOT-2) were measured pre- and post-intervention. The intervention consist of a high intensity physical trainings period (High intensity interval or power training) of 12 weeks, 3 combined with three multidisciplinary meetings to inform the parents. Feasibility was measured by the participation rate, numbers of adverse events, reached training goals, and rated feasibility on a 10-point scale (0= not feasible, 10= very feasible). Effectiveness was determined by progression (mean(SD) and reliable change index (RCI) in physical functioning.

Results: 9/10 children completed at least 90% of the trainings sessions, no adverse events occurred, and 8/10 children achieved their training goals. The rated feasibility was 8.0(1.3) for parents and 8.0(1.1) for children. The scores on the FTT (+1.6(1.8) minutes, p=<.001, RCI= 5/10), MPST (mean power +59,8(96.1)watt, p=.012, RCI=3/10), and BOT-2 +11(6.7) points (p=.336, RCI=8/10) improved.

Conclusion: This pilot study showed that a highly intensive training program, combined with multidisciplinary meetings is feasible and effective to improve physical functioning in children with HCTD.

Relevance for users and families:

Children with HCTD are often cardiac affected and therefore treated with great caution. With this study we discovered safe boundaries within these children can train to improve their physical functioning.

Gait training in congenital insensitivity to pain with anhydrosis induced Charcot hip: A case report

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Introduction: Congenital insensitivity to pain with anhidrosis (CIPA) is a rare hereditary disease that primarily affects the sensory and automatic nerves. We describe a case of patient with CIPA induced Charcot hip who underwent gait training.

Case presentation: 16-year-old boy presented gait disturbance and both hip deformities. At 2 years old, right hip was dislocated after jumping. He got conservative management. However, he didn't feel any pain and frequently moved the pelvis, which caused repeated inflammation. With the fact that he didn't sweat, he was clinically diagnosed with CIPA. At 6 years old, mental retardation was confirmed (IQ =56).

At 15 years old, infectious spondylitis and paravertebral abscess at T11-L2 level with spinal cord compression were found on MRI after falling off a horse. He got posterior fusion of vertebrae, however, he couldn't walk as before. The muscle powers of lower limbs were more than grade 3, and hip flexion contractures were found (10°/5°). On the X-ray, right hip was dislocated and left femur head couldn't be found due to osteolysis.

He started physical therapy(strengthening, gait training, ergometer) twice a week. One day, he had a fever and swelling on right ankle and osteomyelitis with cellulitis was diagnosed. After consultation with his parents, treatment continued. After 8 months of rehabilitation, berg balance scale improved from 4 to 45, and he could walk indoors independently.

Conclusion: We can find that gait training is worthwhile and effective in patient with CIPA induced Charcot hip, however, scar, swelling, fever should be checked frequently.

Relevance for users and families:

There's no relevance for users and families. The authors have no relevant financial or non-financial interests to disclose.

A highly intensive activity-based balance camp for children with Developmental Coordination Disorder – a pilot study on its feasibility and effectiveness.

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Introduction: Up to 87% of the children with Developmental Coordination Disorder (DCD) experience balance deficits, limiting daily participation (e.g. sport- and leisure activities). There is high demand for balance-focused training in children with DCD. However, current literature on this topic is limited. Furthermore, a highly intensive (minimum of 30 therapy hours and 3x/week therapy frequency) activity-based approach appeared successful in other pediatric populations, but is only scarcely investigated in children with DCD. Therefore, this pilot study aims to investigate the feasibility and effectiveness of a highly intensive, comprehensive balance training camp on balance control in children with DCD.

Patients and Methods: Twelve children (9 boys, 3 girls; mean age (SD) = 9.41 (2.3)) with DCD received 35 hours of therapy (divided over 5 consecutive days). Therapy was individually tailored (1:1 ratio participant/therapist), targeted the multisystemic balance framework of Horak et al (2006) and was divided into six activity categories. Feasibility (enjoyment scales: smileyometer 0-5 and qualitative interviewing) and effectiveness (balance control: Kids-BESTest) were investigated. Descriptive statistics and Wilcoxon signed rank test (sign. $p<0.05$) were used to determine interventional effects.

Results: Median enjoyment scale scores showed that children liked all activity categories (minimum: 4/5, median: 5/5, maximum: 5/5). Qualitative interviewing revealed parent-reported motor (7/12 parents; e.g. improved walking pattern) and socio-affective (12/12 parents; e.g. self-confidence, joy of moving) improvements. The overall Kids-BESTest score ($p=0.034$) and the domain 'Stability in gait' score ($p=0.006$) improved.

Conclusion: Preliminary Results suggest that a highly intensive activity-based balance camp is feasible, fun and improves balance.

Relevance for users and families:

This pilot study is the first to investigate the effects of a highly intensive comprehensive balance intervention. Results are promising and a stepping stone towards future balance training programs. By receiving targeted, individually tailored, balance therapy, children with DCD are expected to experience success, and as such their self-esteem and participation in daily life activities may increase.

How do therapists teach children with Developmental Coordination Disorder motor skills? An interview study

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Introduction: Knowledge about the clinical decision-making process of therapists in choosing motor learning strategies (MLSs) when treating children with Developmental Coordination Disorder (DCD) is currently lacking. Therefore, this qualitative study aimed to explore therapists' use of MLSs when teaching motor skills to children with DCD.

Materials and Methods: Semi-structured individual and focus-group interviews were conducted with pediatric physiotherapists having wide range of experience in treating children with DCD. A conventional content analysis approach was used in which all transcripts were open coded by two reviewers. Categories and themes were discussed within the research group. Data was collected until saturation was reached.

Results: Twenty-six therapists (median age: 49 years; range: 26-66) participated in 12 individual and two focus-group interviews. Six themes were identified: (1) therapists treat children in a tailor-made way; (2) therapists' teaching style was either more indirect or direct; (3) therapists used various strategies to improve children's motivation; (4) therapists had reached the optimal level of practice when children were challenged; (5) therapists gave special attention to automatization and transfer; and (6) therapists considered task complexity when choosing MLSs.

Conclusion: Therapists' clinical decision-making processes in choosing MLSs appeared strongly influenced by therapist characteristics, like knowledge and experience, resulting in large variation in the use of MLSs and teaching styles to enhance motivation, automatization, and transfer. This study indicates the importance of the level of education on using MLSs to teach children motor skills, and clinical decision-making. Future research should focus on implementing this knowledge into daily practice.

Relevance for users and families:

Therapists should know that their clinical decision-making process in choosing MLSs to teach motor skills to children is strongly influenced by their own knowledge, experiences and beliefs. In children with DCD, they should give special attention to motivation, automatization and transfer in their treatment. For educators, this study indicates the importance of the level of education on using MLSs to teach children motor skills and clinical decision-making.

Therapists' use of instructions and feedback in motor learning interventions in children with Developmental Coordination Disorder: a video observation study

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Introduction: Practical recommendations on therapists' use of motor learning strategies to teach motor skills to children with Developmental Coordination Disorder (DCD) are currently lacking. As a first step in developing these recommendations, this qualitative study explored therapists' use of instructions and feedback when teaching motor tasks to children with DCD.

Materials and Methods: A conventional content analysis approach was used to analyse video-taped treatment sessions of physiotherapists using a newly developed plan. Inductive coding was used to code purposively selected video segments. The codes were sorted into categories to identify key themes. Analyses were performed independently by two researchers, data was collected until saturation was reached.

Results: Ten video-taped sessions were analysed and 61 segments coded. Three key themes were identified: (1) 'therapists' intention with the instructions and feedback' was either to motivate or to provide information; (2) the preferred 'therapists' teaching style' was either direct or indirect; and (3) 'parameters to shape specific instructions and feedback' were focus, form, information content, timing and frequency.

Conclusion: Therapists used numerous instructions and feedback with different information content, often shaped by multiple focuses and/or forms to motivate children or to provide specific information about task performance. Although therapists adapted instructions and feedback to child and task, future research should explore how the characteristics of these can guide therapists' use of instructions and feedback.

Relevance for users and families:

For teaching motor skills to children with and without DCD, physical and occupational therapists, sports trainers, and physical education teachers should use instructions and feedback to motivate them or to provide them with specific information about the task performance. They can use parameters like focus, form, information content, timing and frequency to shape their instructions and feedback in numerous ways, while adapting these to the individual child and task practised.

An intervention protocol of a highly intensive activity-based balance training camp in children with Developmental Coordination Disorder

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Introduction: Developmental Coordination Disorder (DCD) is a neurodevelopmental disorder that is characterized by clumsy, uncoordinated movements and affects all F-words of childhood disability (functioning, family, fitness, fun, friends and future). Up to 87% of these children experience balance problems (fitness), impacting their daily participation (functioning, friends, family) and resulting in potential consequences on self-esteem and mental health (fitness, fun, future). There is high demand for focused balance training. However, current literature on this topic is limited.

Patients and Methods: Based on this study protocol, we will investigate the effects of a highly intensive individually tailored, six-day functional balance camp in children with DCD. We will investigate effects on balance control (fitness), neuromuscular processes (fitness), self-perceived competence (fitness, fun), self-chosen goals (future, fun) and participation (functioning, friends, family). Based on sample size calculation, we aim to recruit 48 children with DCD (6-12 years) who will receive 40 hours of focused balance training. This intervention is designed to be fun, comprehensive, and includes individual and group activities. The functional therapy is individually tailored (1:1 therapist-child ratio) and implements different motor learning strategies. Participants will be assessed pre- and post-interventional, including 3- and 6-months follow-up.

Conclusion: This study protocol will be the first to target balance control with a comprehensive balance training camp and investigate outcome measures at all levels of functioning (all F-words).

Relevance for users and families:

This protocol will provide novel insights into balance control and the control mechanisms involved in children with DCD. It is transferable towards various clinical practice situations and can therefore reach a large number of children with DCD. By receiving comprehensive, individually tailored, goal-directed balance training, children with DCD are expected to experience more motor successes (fun), and as such their self-esteem (fitness, fun, future) and participation in daily life activities (functioning, friends, family) may increase.

Development of a screening version of the Hand Assessment for Infants for infants at risk of unilateral cerebral palsy

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Introduction: There is a need of a screening tool for identification of unilateral cerebral palsy (UCP) that is easily accessible and simple to use. We will investigate whether a short version of the Hand Assessment for Infants (HAI) can be performed by parents at home and recorded using a smartphone app, for infants between 3,5-12 months of age.

Materials and Methods: To reduce the original HAI item set and develop the screening HAI (s-HAI), receiver operating characteristics curve analysis was used. To date we have collected data from 22 families using the s-HAI and HAI performed in clinic. Parents performed five minutes recordings which were reviewed for quality to serve as a base for scoring. Three raters independently scored sixteen recordings for interrater reliability and the Intraclass Correlation Coefficient was calculated. The relation between scorings from s-HAI and HAI was analyzed using Spearman's correlation. Parents' experience was evaluated using a questionnaire.

Preliminary Results: A set of 6 items with 86% accuracy to correctly classify infants with and without UCP was used for further investigation. The interrater reliability of s-HAI was 0,87-0,94 and the relation between HAI and s-HAI scores was 0,81. Parents performed the recordings with good quality and only two had to redo the recording. Nineteen out of 22 parents preferred to do the recording at home instead of at the hospital.

Conclusion: In the first step, the selected item set makes s-HAI a promising tool for screening and identifying infants at risk for UCP with high interrater reliability.

Relevance for users and families:

s-HAI will be able to facilitate earlier identification of infants at risk of UCP with the advantage of being easily accessible for both parents and health professionals. Health professionals can use s-HAI after completing an online course.

Parents' experiences with the PlayfulBrain programme: a pilot study.

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Introduction: Children with Cerebral Palsy (CP) or Traumatic Brain Injury (TBI) are at risk for problems in the development of attention and executive functions (EFs). Interventions targeting attention and EFs in young children are not typically available in clinical practice. Recently, the book PlayfulBrain, for parents of 0-4 year olds, was published. It consists of psychoeducation on attention and EF development and games targeting these aspects through parent-child play. We investigated experiences with the PlayfulBrain programme and whether parents will play using the book.

Patients and Methods: 9 children with CP and 2 children with TBI were included. First, children were administered an EF test battery. Second, the PlayfulBrain programme was administered, consisting of a 15-minute psychoeducation video and a supervised 1-hour play session with parent and child, in which a researcher showed and explained how to play PlayfulBrain games. Six weeks later, a semi-structured interview took place. Measurements furthermore consisted of a play-diary (2x/week for 6 weeks) and questionnaires.

Results: All parents played PlayfulBrain games with their child during the six-week period. Parents were positive about the programme, but found it challenging to incorporate the dedicated play in daily life.

Conclusion: Delivering the PlayfulBrain programme leads to parents playing games targeting EF development with their child.

Relevance for users and families:

Further research should examine whether playing PlayfulBrain games leads to, for example, more advanced development of EFs in children. This knowledge will benefit parents and children, because there are yet few programmes that successfully stimulate early EF development.

Measures of parent enactment of home-based interventions for infants with unilateral cerebral palsy – a pilot study

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Introduction: Enactment is the extent individuals perform intervention in daily life. Parent enactment has not been reported in early intervention trials for unilateral cerebral palsy (UCP). Objective measures of enactment are essential to accurately evaluate intervention outcomes. Purposes of this study were to describe parent-reported enactment and explore Methods to quantify enactment of home-based, parent-directed complex interventions for infants.

Patients and Methods: N=12 infants at high risk of UCP, aged 3-9 months at entry, from a single intervention site of a randomized comparative effectiveness trial (Rehabilitation EArly for Congenital Hemiplegia, REACH). Parents self-reported intervention hours (dose) using Parent Diaries. Video-recorded home intervention sessions were coded for goal-related activities and activities unrelated to goals using (a) continuous duration, (b) 1-minute partial-interval time sampling, and (c) a checklist of key intervention components.

Results: Parents reported 0.33-19.73 intervention hours per month compared with the intended range of 6.7-13.3 hours per month, dependent on the infant's age. 34.2% of diary data were unreported. All parents provided opportunities for goal-related activities [median, 60.1% of time (continuous duration); 93.3% of session minutes (partial-interval time sampling)]. Median (IQR) checklist score was 14 (11.75, 14.25) out of 16. Scores were higher when opportunities for goal-related activities were more frequent.

Conclusion: Parent diaries were a variable, incomplete measure of time enacting intervention. Continuous duration and partial-interval time sampling may provide an objective measure of goal-related activities performed. Partial-interval time sampling was more time-efficient but over-estimated goal-related activities. The checklist was a gestalt measure of quality of intervention activities performed.

Relevance for users and families:

Accurate recording of intervention time using diaries is challenging. Using video-recorded intervention videos, we were able to measure what activities were performed by parents with their infant and how long activities occurred. This is a more accurate way to capture the amount of intervention parents performed with their infant. Our Results can improve our recommendations for the amount of intervention needed for individuals to achieve their goals.

INCREASE - an ongoing study - Feasibility of performing an interdisciplinary quantitative research intervention for families with infants at high risk of cerebral palsy.

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Introduction: The current line of evidence supports early detection and interventions for families with infants at high risk for cerebral palsy (CP). Muscular challenges have been shown to appear at an early age and may become a lifelong challenge for social integration and participation. Thus, early intervention to prevent muscular changes is pivotal in helping motor and cognitive development. In parallel, recent clinical guidelines on early intervention among families with infants at risk of CP recommends supporting parental sensitivity and mutual enjoyable interactions. The focus of this study is, thus, to combine these different perspectives recognizing the need of supporting parents and their wellbeing when aiming to enhance infant outcome.

Participants and Methods: Infants at around 15 weeks corrected age diagnosed with CP or designated at high risk of CP based on abnormal neuroimaging or absent fidgety movements (FM) as determined by General Movement Assessment (GMA) are included. The intervention lasts for six months aiming to guide and support parents in providing daily individualized, goal-directed activities. The study aims to assess the quality of early parent-infant interaction using developmental assessments, questionnaires, and interviews with both parents. The study follows the infants until the age of four.

Results and Conclusion: Two years post first inclusion, 15 infants are included and nine have completed the intervention. It is still too soon to conclude anything based on our data. However, preliminary experience emphasizes that interdisciplinary research with heterogenous participant is difficult though possible to practice. It seems feasible to combine the two perspectives.

Relevance for users and families:

Randomized controlled clinical trials are challenging and can be difficult ethically, however, it is crucial to fully understand the actual effect of an intervention to optimize clinical practice. Furthermore, it is essential and of great value for future research and clinical practice that we as scientists and practitioners continuously share experiences and knowledge.

Can intensive unimanual (CIMT) and bimanual (HABIT) motor interventions improve visuospatial performance in children with unilateral cerebral palsy? A randomized controlled trial

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Introduction: Although visuospatial attention deficits have been described in many children with unilateral cerebral palsy (UCP), it is unknown whether Constraint-Induced Movement Therapy (CIMT) or Hand-Arm Bimanual Intensive Therapy (HABIT) may result in visuospatial improvements. Such effects might be differential in children with right or left hemiparesis due to the lateralization of the visuospatial circuitry in the brain.

Patients and Methods: 64 children were randomized to receive CIMT or HABIT, both involving 90 hours of intervention (6hours/day, 5 days/week for 3 weeks). Four visuospatial tests (Ogden figure copy, Star cancellation, Line bisection and Proprioceptive pointing) were performed before and after the interventions. A 2(time)×2(group) mixed model ANOVA or non-parametric ANOVA were used on the whole sample, and separately in children with left (n=27) and right (n=37) hemiparesis .

Results: When testing the whole sample, no global effect of treatment was detected. An interaction indicated a larger improvement for CIMT in the Ogden Figure Copy(p=0.032). In children with right hemiparesis, a significant treatment effect in both treatments was observed for the line bisection test(p=0.035). Children improved their performance in the Ogden Figure Test with CIMT (p=0.025). In children with left hemiparesis, improvements on the star omission was observed in the right hemispace for both treatments (p=0.021). Children improved their performance in the star cancellation in the left hemispace (p=0.009).

Conclusion: Unimanual and bimanual intensive interventions appear to stimulate different aspects of visuospatial attention processing in children with UCP. Effects likely depend on the brain side preferentially involved in the visuospatial circuitry.

Relevance for users and families:

Understanding which intensive therapy (unimanual or bimanual) is more effective to improve some aspect of the visuospatial performance of children with UCP is of huge interest to better tailor one of these interventions depending on children's characteristics.

Multidisciplinary intervention program before spinal surgery in spinalmuscular atrophy. A case report

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Introduction: The case is a 10-year-old girl with Type II Spinal Muscular Atrophy (SMA), who has been a candidate for spinal surgery with conventional bars. Since then, to the previously running Physical Therapy program, we add Psychology to create a multidisciplinary intervention program to prepare for the surgery.

Patients and methods: The patient was diagnosed with Type II SMA and has been part of a multidisciplinary intervention program for a year. The program is run by the authors, and it includes both a great amount of individual intervention and a family-centered period.

During the pre-surgical phase, the girl has three sessions per week in the center, two devoted to Physical Therapy and one to Psychology. The objective is to maintain the global functionality, prepare the muscle-skeleton and respiratory systems, furnish strategies to cope with the situation, and reduce anxiety.

Results: In the structure of the Physical Therapy program, the abilities obtained previously to the participation in the multidisciplinary intervention program are maintained, and the aim is to improve the new abilities related to daily life activities. The psychologist aids in the learning of new coping and anxiety management strategies.

Conclusion: This case proofs how a pre-surgical multidisciplinary approach in such a complex case, both surgically and emotionally, can ease the patient's recovery, reducing the time and improving the quality of how the patient can fall back into her routines after the surgery.

Relevance for users and families:

This change in the way of coping with difficulties has allowed her to make progress in the acquisition of new complex functional abilities, due to an improvement in the patient's security and rationalization capabilities.

The family has also been assisted. Their cooperation to spread these advances and learning processes has been basic.

Early results of vojta therapy in down syndrome: a case report

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Introduction: In this case report, we aimed to present the early Results of 5-month Vojta therapy in a person with Down syndrome

Patients and Methods: The pre- and post-treatment evaluation of the case with a genetic diagnosis of released trisomy began with a demographic evaluation. Classical motor and Gross Motor Function Classification System (GMFCS) evaluations were used to determine the motor development level of the case. Evaluation of muscle tones was evaluated by palpation and the patient's innate postural response ability (postural reactivity) was evaluated with 7 postural reflexes according to Vojta. The patient was treated with vojta therapy 2 days a week for 5 months.

Results: According to classical motor assessment before and after treatment, respectively; Progressed from the phase where poor head control and negative standing on the forearms to the phase where head control, forearms and hands on stand, supported sitting, turning and crawling are positive. According to GMFCS, it was found that there was an improvement from level 5 to 3, and on palpation, hypotonus decreased after treatment. According to Vojta, in the postural reactivity assessment; it was determined that there was an improvement from mild central coordination disorder to very mild central coordination disorder.

Conclusions: It is important to apply Vojta therapy in the earliest period for the motor development retardation and hypotonus-cocontraction problems associated with muscle tone and balance and correction reactions seen in children with Down syndrome.

Keywords: Down, Vojta, GMFCS

Relevance for users and families:

Families with a child with Down syndrome experience motor development problems as well as additional health problems in their children. Early motor intervention is very important to overcome motor development problems in the early period. Vojta therapy is very useful in children with Down syndrome, as we mentioned in our case report, in early returners.

Visual-motor abilities in children being assessed for fetal alcohol spectrum disorder

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Introduction: Children with prenatal alcohol exposure often have different profiles of learning and abilities than children without. The aim of this study is to describe the visual-motor integration, visual perception and motor coordination pattern of abilities in children with prenatal alcohol exposure being assessed for fetal alcohol spectrum disorder (FASD).

Patients and Methods: This cross-sectional study included 91 children (65 males; mean age: 10 years, 6 months; SD=2 years, 10 months; range 6–17 years) undergoing assessment for FASD. Friedman test and Wilcoxon signed rank test were used to compare mean visual-motor integration, visual perception, and fine motor coordination percentiles from the Beery-Buktenica Developmental Test of Visual-Motor Integration.

Results: Children being assessed for FASD (n=91) performed highest in visual perception followed by visual motor integration and then fine motor coordination ($\bar{x}$ percentiles (SD): 35.9 (24.9), 20.6 (18.3) and 13.8 (15.5), respectively)

Differences in assessment scores across the tests were statistically significant ($\chi 2(2) = 46.909$, $p < 0.001$).

Conclusions: Results provide evidence that children being assessed for FASD experience more challenges with fine motor coordination compared to visual-motor integration and visual perception tasks. This pattern differs from the pattern established for the general population (i.e., greatest challenges with visual-motor integration). These Results suggest that fine motor coordination should be included in FASD diagnostic assessments and be considered for occupational therapy intervention.

Relevance for users and families:

Relevance for Users and Families: A comprehensive visual motor assessment that includes motor coordination can help ensure that resources and supports are targeted at diagnosis to maximize the potential of children with prenatal alcohol exposure and build on their strengths.

A critical view on motor-based interventions to improve motor skill performance in children with Attention Deficit Hyperactivity Disorder: A systematic review and meta-analysis

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Introduction: Children with Attention Deficit Hyperactivity Disorder (ADHD) often experience motor skill difficulties (prevalence: 30-60%), potentially impacting their self-esteem, physical fitness and sedentary behavior, which eventually Results in social isolation. However, no recommendations towards the use of motor-based interventions are included in international clinical practice guidelines for the treatment of children with ADHD. As such, we aimed to map the effectiveness of motor-based interventions to improve motor skill performance in children with ADHD.

Methods: A systematic literature search was performed in Pubmed, Web of Science and the SCOPUS database (last search: 30/10/2022). Studies were included if they investigated the effectiveness of any motor-based intervention for children aged 2 to 18 years old, with a standardized developmental motor scale. Methodological quality was assessed using the PEDro-scale. The quality of evidence was determined with the GRADE-method.

Results: Thirteen studies (including 399 participants; 7 RCTs) satisfied the inclusion criteria, five of which were eligible for meta-analysis. Only one study reached the low risk of bias threshold. Comparing different motor-based interventions to any non-motor control intervention showed large motor skill improvements (SMD=1.46; 95% CI=[1.00;1.93]; I^2=47.07%). The most effective type of motor-based intervention and the optimal treatment parameters remain undetermined.

Conclusions: Motor-based interventions in general seem to improve motor skills in children with ADHD. Additional RCTs are needed to increase current low GRADE confidence. Future studies should clearly describe the rationale for the intervention used and the training methodologies, following the TIEDieR guidelines, allowing to establish optimal treatment parameters.

Relevance for users and families:

Motor skill deficits may result in long-term consequences such as lower levels of physical fitness, sedentary lifestyle, secondary health problems and social isolation. Interventions to diminish these deficits are urgently needed. Our findings should encourage physical education teachers, sport instructors and clinicians to put more emphasis on training motor skills needed for an active lifestyle. Our Results hopefully inspire researchers to further investigate which type of motor-based therapy can best improve motor skill performance.

Effectiveness of early vestibular stimulation exercise in prognosis of Bilirubin Encephalopathy- a case study

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Introduction: Bilirubin encephalopathy (BE) is the result of prolonged bilirubin toxicity resulting in widespread neurological injury. Once the bilirubin levels are normalized the encephalopathy becomes static, however the consequences of the injury can have life-long effects. The sequelae of BE include motor impairments, auditory deficits. Literature on the treatment of various specific sequelae of BE is varied, but in general specific therapeutic efforts to improve motor skills are not evidenced-based. The following is a case report on the use of Vestibular stimulation exercise to ameliorate some of the motor-function deficits secondary to BE.

The aim of this study was to assess the efficacy of a vestibular stimulation exercise in improving motor functions and auditory processing in these children.

Methods: This case-report presents the Results of intensive vestibular stimulation exercise in one male child with BE. The child was diagnosed with BE at day 4 after birth. He was assessed with General movement assessment at 2nd week and 14th week of corrected age. He was also assessed with Behavioural observation audiometry with visual reward (VAR) at same time. The child was assessed before and after treatment with standardized measures, the Gross Motor Function Measure (GMFM) and The Bayley Scales of Infant and Toddler Development (Bayley) and VAR.

Result: Child showed significant improvement in GMFM, Bayley and VAR assessment.

Conclusion: Vestibular stimulation exercise proved to be an effective complementary strategy for facilitating motor functioning and auditory processing.

Relevance for users and families:

Early detection and early intervention (Vestibular stimulation exercise) can make better prognosis in children with Bilirubin encephalopathy.

Recognition of Movement Qualities of Children with Developmental Coordination Disorder: An Exploratory Study

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Background: Great attention has been given to ameliorating movement skill deficits among children with developmental coordination disorder (DCD) with not enough emphasis placed on how motor skill deficits are presented.

Objective: The objective of the study was to profile movement characteristics of children with DCD between 6-15 years of age.

Methodology: The study adopted a qualitative study design with a grounded theory approach. Children diagnosed with DCD through DSM-5 criteria. 15 Fundamental movement skills (FMS) were captured through a standardized video recording setup and were processed into Kinovea software for movement analysis for four children with DCD. Each child's FMS was transcribed into codes using the pre-validated syntax of movement analysis. Through this constant comparison, codes were grouped together to form a theme or category. The interrelationship between the concepts was attempted to explain the latent pattern of motor skill deficits.

Results: Of the total of 2286 children between the age of 6-15 years who were initially identified for the study, 16 children were diagnosed with DCD, and 48 TD children were chosen for profiling movement characteristics. The movement profiles of children with DCD predominantly exhibited: Reliance on visual input predominantly for the accomplishment; Constraint movement pattern; Recruitment of inappropriate, uncoordinated, and inconsistent use of remote body segments with respect to space; Strenuous movement pattern indicating insufficient power generation and inefficient energy dissipation

Conclusion:Clear differences in the movement pattern of children with DCD were evidenced as compared to TD children.

Relevance for users and families:

Proficiency in movement skills is a prerequisite for daily functioning and social participation which takes place under various environmental circumstances. Abnormal movement characteristics early in life may lead to low-level variations in the neural organization that over a period may lead to unique irreversible and potentially uneven profiles. Thus identified trajectories can in turn be used to intervene in the child with DCD efficiently and effectively

Gait analysis in children with cerebral palsy in consultation: are we doing our best?

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Introduction: Cerebral palsy (CP) is a neurodevelopmental disorder that begins at birth or early childhood and persists through life. CP is usually accompanied by different alterations such as the ability and co-ordination for walking (gait).

Gait evaluation is used to determine the degree of involvement or the cause of the gait abnormality and can be used as an outcome measure to evaluate change and the effectiveness of an intervention.

Instrumented gait analysis is the gold standard for the evaluation of movement but requires highly technological equipment and it is not always available for our consultations. Observational gait assessment, usually using the Edinburgh Visual gait Score (EVGS), is considered as a cost-effective alternative to instrumented gait analysis in regular clinical practice.

There are some other Methods for gait evaluation which may be accessible for routine clinical work, such as the use of inertial sensors, visual scales or software for video analysis.

Patients and Methods: The gait of 7 patients with CP was reported using the EVGS by an experienced and an inexperienced doctor, and compared to a gait report automatically generated with inertial sensors (Xsens Awinda).

Results: Introducing inertial sensors for gait analysis in the clinic provides quantitative data and curves useful for kinematic assessment and patient follow-up. It can be used to the advantage of the inexperienced doctor over the experienced one.

Conclusion: Gait analysis using both EVGS and inertial sensors allows for better decision making in gait management regardless of the degree of experience of the physician.

Relevance for users and families:

Relevance for users and families: Improving PC gait analysis will improve decision-making and treatment outcomes.

Spontaneous movements and cortical activation in infants at-risk for cerebral palsy: Use of functional near-infrared spectroscopy to identify potential therapeutic targets

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Introduction: Spontaneous movements predominate the newborn motor repertoire. Assessment of the quality of spontaneous movements serves as a critical tool for the identification of infants at high-risk (AR) for cerebral palsy (CP). Spontaneous movements also serve as a potentially rich source of feedback for developing sensory systems. Functional near-infrared spectroscopy (fNIRS) is an optical imaging technique that permits measurement of cortical activity during naturalistic movements. The goal of this study was to track spontaneous movements in infants in relation to cortical development using fNIRS.

Patients and Methods: A cohort of typically developing infants and infants AR for CP were longitudinally tracked (monthly) from 2-6 mos. of age. At each session, spontaneous movements in supine position were observed for 5 minutes. Movement bouts were recorded using wearable sensors on the arms and legs. Cortical activity was measured using an fNIRS probe (8 sources, 12 detectors) that covered bilateral sensorimotor areas.

Results: Bouts of movement were more frequent in TD compared to AR infants ($p<.01$) and longer in duration ($p<.05$). In TD infants, movement bouts elicited greater bilateral activation of sensorimotor areas compared to when the infant was at rest (i.e., no movement occurring). AR infants demonstrated aberrant and reduced patterns of cortical activation.

Conclusion: These data suggest that there are pronounced movement differences, and resulting cortical activity, that characterize typical and atypical motor development trajectories. Thorough descriptions of the interrelation between spontaneous movements and developing cortical function may provide insights into potential behavioral targets for infants AR for CP.

Relevance for users and families:

In typically developing infants, patterns of movement that seem random and do not have a specific function may actually contribute to development of brain areas responsible for the control of movement. Understanding these patterns, and how such patterns may differ in infants at-risk for CP, will allow us to identify behaviors that could be targeted with movement therapy.

Morphological muscle growth in infants and toddlers: a longitudinal study

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Introduction: Only cross-sectional observations defined muscle growth alterations from early ages in children with cerebral palsy (CP). Consequently, insights in the longitudinal trajectories of muscle growth are missing. We aimed to model medial gastrocnemius muscle growth in infants and toddlers with and without CP and compare the longitudinal trajectories for the level of gross motor function classification system (GMFCS) and the presumed brain lesion timing.

Patients and Methods: Twenty typically developing (TD) children and 24 children with CP (GMFCSI-II/GMFCSIII-IV=15/9) were included (28/16 females/males; mean age 15.4 months (SD 4.93 months, range 6.24-23.8 months at inclusion)). 3D freehand ultrasound was used to repeatedly assess muscle volume (MV), length, and cross-sectional area (CSA), resulting in 138 assessments. Linear mixed models were applied comparing muscle growth rates between children with GMFCSI-II and GMFCSIII-IV, and between children with presumed early (predominant white matter) and late (predominant grey matter) brain lesion timing.

Results: At age 12 months, children with CP showed muscle size deficits compared to TD children ($p<0.001$), while subsequent muscle growth was found with increasing age in children with and without CP. MV and CSA growth rates were lower in children with GMFCSIII-IV compared to TD and GMFCSI-II ($p<0.001$). Muscle growth trajectories were comparable for the presumed brain lesion timing.

Conclusion: Medial gastrocnemius muscle growth is hampered already during infancy in CP, most likely due to altered neural input and limited motor functioning. Muscle size growth rates further reduce with decreasing functionality. Early monitoring of muscle growth combined with early intervention is suggested.

Relevance for users and families:

This longitudinal study indicates an early status of altered muscle growth. Consequently, early detection and early intervention should be considered in the clinical follow-up of infants with cerebral palsy.

Fun, Innovative Therapy Intervention for Children with Hemiplegic Cerebral Palsy: Constraint-Induced-Movement-Therapy Summer Camp

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Introduction: Children with hemiplegic cerebral palsy (CP) face challenges using their two hands in bimanual tasks. The Constraint-Induced-Movement-Therapy (CIMT) Summer camp of the Lethbridge-Layton-Mackay Rehabilitation Centre is an innovative way to provide intervention to children with similar needs through fun, therapeutic activities.

The use of a constraint on their dominant hand, combined with bimanual therapy are among best practices to develop and improve the function of their most affected hand.

This approach enhances children's participation in meaningful self-selected goals involving daily bimanual activities.

Patients-Methods: The CIMT camp is offered to a group of 8 children between 6-12 years old. They have access to therapy through an intensive 12-day camp, over 3 weeks, co-animated by an Occupational Therapist, Physiotherapist, Specialized Educator and a Camp Counsellor; former camper living with hemiplegic CP.

Pre-post assessments are conducted with tools developed to determine the efficacy of interventions on unilateral and bimanual functions; including grip, pinch strength, ROM and functional use. The COPM identifies client's-centered-goals and the CO-OP approach supports the development of strategies.

Results: Campers consistently improve on standardized testing. They achieve their goals and sustain these Results, which positively impact their daily life. The benefit of having children with similar experiences is powerful, combined with a camp counsellor who serves as a model for the kids and parents.

Conclusion: Combining CIMT and bimanual therapy is a proven approach for children with hemiplegia. It provides a fun, intensive intervention that has many benefits, not only on improving movement for functional tasks, but overall well-being.

Relevance for users and families:

The CIMT camp provides a safe space for children with hemiplegic CP to meet other kids with similar needs, as well as challenge themselves and push their limits in a therapeutic, supportive, fun environment. During this 3 weeks intensive period, campers come up with their own goals and strategies, which yields satisfaction and empowerment. Families are also provided with tools involving the integration of strategies during daily homework, and gain hope, witnessing the positive changes.

The effect of Functional Electrical Stimulation (FES) during walking in unilateral spastic cerebral palsy: the FES on participation (FESPa) trial

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Introduction: We studied if functional electrical stimulation (FES) of the peroneal nerve improves participation in daily life and whether FES has effects on gait in children with unilateral spastic cerebral palsy (usCP).

Patients and methods: A randomized crossover trial was performed in 25 children aged 4-18 years with usCP (Gross Motor Functioning Classification System level I-II). The study consisted of two twelve-week blocks of treatment: conventional and FES, separated by a six-week washout-phase. Outcome measures included Goal Attainment Scale (GAS), CPQoL questionnaire and 3D-gait analysis.

Results: Eighteen patients completed the trial. The proportion of GAS goals achieved was not significantly higher in the FES phase versus conventional phase (goal 1 p=0.065; goal 2 p=1.00). During walking with FES, ankle dorsiflexion in mid-swing decreased over 12 weeks time (p=0.006), with a preserved increased ankle range of motion compared to conventional treatment (p<0.001). No changes were found in standard physical examination, satisfaction with orthosis, nor for feelings about dressing. In four patients FES therapy failed and in twelve patients FES therapy was continued after the trial.

Conclusion: FES is a suitable alternative to conventional treatment for some patients with CP, but critical patient selection using a testing period and thorough follow-up is needed.

Relevance for users and families:

RELEVANCE: It is important to study alternative treatments because some patients are not satisfied with conventional therapy (mostly ankle foot orthoses). Problems include pain (due to pressure points) or too much restriction of movement.

Central and peripheral components of neuromuscular fatigue in individuals with cerebral palsy and typically developing peers.

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Introduction: Neuromuscular fatigue (NMF) is one of the main limitations for individuals with cerebral palsy (CP). Its underlying neurophysiological mechanisms are still debated. The study aimed to determine the contribution of central and peripheral NMF components in individuals with CP and typically developing (TD) peers. We hypothesized that the impaired neural drive in CP would exacerbate the level of central NMF.

Patients and Methods: Fourteen participants (7 CP, 7 TD) performed a neuromuscular evaluation of the quadriceps muscle before- and after isometric fatiguing exercise (Ex). Central and peripheral components of NMF were assessed: maximal voluntary contraction (MVC), electrically-evoked resting twitch (Qtwpot), voluntary muscle activation (VA) and electromyographical-related (EMG) parameters. To allow additional comparisons, TD peers performed an additional session (IsoT-Ex), exercising at the same Torque-target of their CP-match.

Results: Before exercise, MVC, Qtwpot and VA were lower in CP, even when adjusted for leg muscle volume, but they did not decrease after exercise. Similarly, EMG-related parameters in CP group remained constant throughout exercise. Individuals with CP had longer time-to-exhaustion (CP: 35’20” ± 3’57”, TD: 9’57” ± 3’30”). Surprisingly, fatigue-induced changes in TD peers were higher than CP even during IsoT-Ex session.

Conclusion: Individuals with CP were weaker than TD and characterized by sub-optimal muscle activation. However, they exercised for longer time at relative high intensity. The Results suggest the incapability of fully recruiting motor units in CP, resulting in underestimating the MVC and allowing turn-over at motor unit level. Yet, our findings can also be partially explained by muscular adaptation.

Relevance for users and families:

This study investigates which component of neuromuscular fatigue is more limiting for the execution of functional daily-life activities in individuals with cerebral palsy. Our findings emphasize the need for developing specific training interventions (i.e., tailored strength training) to target especially the neural components of force production, and thus decrease the gap in muscle recruitment for individuas with cerebral palsy.

Immune cell status and response to acute endurance exercise in young adults with cerebral palsy

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Introduction: Children with cerebral palsy (CP) suffer from chronic low-grade inflammation and present altered immune cell proportions. However, whether immune status and function are altered in adults with CP is not known. This study aimed to quantify the proportions of circulating immune cells and their response to acute endurance exercise in young adults with CP.

Patients and Methods: Blood samples were collected from 12 individuals with CP (25.1±5.9yr) and 17 typically developing (TD) peers (31.4±6.2yr) before, immediately after, and one hour after 45 minutes of Framerunning or running exercise, respectively. Heart rate, distance, and level of exertion were measured. A repeated measures ANOVA was used to test immune cell proportions between groups and over time. Performance variables were compared with independent t-tests.

Results: The proportions of immune cells did not differ between groups at baseline. However, the CD8+ T-cell proportions differed ($p<0.05$) directly after exercise (TD: +20.4%; CP: +5.4%). Moreover, TD participants reached significantly higher heart rate (+12.2%) and longer distances (+64.3%). Correlation analysis revealed exercise intensity (i.e., heart rate) as a decisive factor for the different responses ($r=.54$, $p<0.01$).

Conclusion: No evidence for altered immune cell proportions was found in young adults with CP at rest. However, we observed a less pronounced increase in CD8+ T-cells after exercise that we interpret as exercise intensity dependent. This suggest that reduced physical fitness may hamper the immune response to exercise in individuals with CP.

Relevance for users and families:

Improving physical fitness in individuals with CP is important to reach training intensities that trigger health-related immune responses.

Individuals with cerebral palsy have an altered ventilatory response to acute incremental exercise

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Introduction: Individuals with cerebral palsy (CP) have impaired motor control resulting in functional limitations, including posture and movement but also in reduced muscle mass. Previous studies have shown that individuals with CP take frequent breaths during intense exercise and that blood lactate levels are elevated during low-intensity exercise. This study aimed to investigate the ventilatory response to incremental exercise in individuals with CP.

Patients and Methods: Fourteen (6 male) individuals with CP, Gross Motor Function Classification System (GMFCS) level II/III/IV/V (n=1/5/7/1), and 30 (14 male) typically developed (TD) participants performed a lactate threshold test. Blood lactate, partial pressure of carbon dioxide (pCO2) and cardiorespiratory parameters including heart rate (HR), respiratory frequency (RF), tidal volume (VT), minute ventilation (VE) and ventilatory efficiency (VE/VCO2) were measured. Data was investigated using a repeated mixed model.

Results: Our Results show that individuals with CP have decreased VE ($p=0.006$) despite increased RF at a given intensity compared to TD ($p=0.01$). In addition, the CP group had a higher VE/VCO2 ratio ($p<0.0001$) throughout the test. The groups behaved differently regarding lactate ($p=0.0003$) and pCO2 ($p=0.07$).

Conclusion: This study suggests that individuals with CP have an altered cardiorespiratory response to incremental exercise with increased RF, low VE, and a tendency for pCO2 accumulation in comparison to TD.

Relevance for users and families:

Relevance for users and families: The altered and decreased ventilation during incremental exercise suggests the importance of training interventions for individuals with CP. As a complement to physical activity, we suggest that respiratory exercises should be included in order to improve ventilatory function.

Plasma extracellular vesicle characteristics and microRNA content in cerebral palsy and typically developed individuals – what is the role of the muscle-specific miR-486?

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Introduction: MicroRNAs (miRNAs) are short noncoding RNAs that regulate mRNA translation influencing numerous biological processes. One mode of transmitting miRNAs from one cell to another is via circulatory extracellular vesicles (EVs). The current understanding of vesicular size, concentration in plasma and miRNA content in individuals with cerebral palsy is limited.

Patients and Methods: Blood was collected from 9 individuals with CP (mean age 27yrs, range 16-44yrs, GMFCS I-V; 0/3/3/3/0) and 10 typically developed (TD) individuals (mean age 28yrs, range 18-40yrs) at rest. EV size and concentration were assessed by nano particle tracking analysis (Zetaview). Small RNA sequencing (pooled RNA samples, n=3-4/pool) was performed on isolated EV. Data was complemented by cell culture and cross-referenced to publicly available CP muscle data sets.

Results: EV size was similar but the concentration was lower (~25%, $P<0.05$) in CP vs. TD. The lethal-7 miRNAs; let-7a, let-7b and let-7e levels were downregulated, and miR-486 upregulated ~2-fold in EVs from CP vs. TD ($P<0.05$). There was a resemblance to publicly available CP skeletal muscle data sets with sarcomere and extracellular matrix related genes observed to be differentially expressed in miR-486 mimetic treated C2C12 myoblasts.

Conclusion: This study provides novel and valuable information on the concentration and properties of EVs in CP individuals. TD and CP participants presented a different EV-transported microRNA profile, with miR-486 plausibly providing a link to skeletal muscle alterations seen in individuals with CP.

Relevance for users and families:

Our data highlights the importance of further exploration and the need for a deeper understanding of physiology in individuals with CP.

Longitudinal association between nutritional status and gross motor function in children with cerebral palsy

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Introduction: Growth is the primary measure of nutritional status. Children with cerebral palsy (CP) frequently grow poorly compared to reference norms. This study examined the association between nutritional status and gross motor function in children with CP.

Patients and Methods: A longitudinal cohort of children with CP (n=186, 60.7% boys) were assessed up to five times for a total of 494 assessments between the ages of 1.5 and 12 years (3.3±2.4 years at recruitment, Gross Motor Function Classification System [GMFCS] I=87, II=23, III=29, IV=21, V=26). Physiotherapists administered the Gross Motor Function Measure (GMFM-66). Weight and length/height/knee-height were measured, and Body Mass Index (BMI) was calculated. Anthropometric data were converted to Z-scores using standard age and gender specific reference data. The longitudinal association between growth Z-scores and GMFM-66 was determined using mixed-effects linear regression models.

Results: Height (B=1.58, 95%CI: 0.45,2.72) for children classified as GMFCS I and II, but not those classified as GMFCS III-V, was positively and significantly associated with gross motor function in children. Weight and BMI Z-score were not associated with GMFM-66 score.

Conclusion: Greater height-for-age was associated with greater gross motor function attainment in children classified as GMFCS I-II. The difference in GMFM-66 associated with one standard deviation difference in height was greater than the minimal clinical important difference in GMFM-66 for children classified as GMFCS II (1.5 units). Regular monitoring of growth and timely dietetic involvement, if necessary, is recommended in children with CP to optimise growth and gross motor outcomes.

Relevance for users and families:

Relevance for users and families: We followed children with CP from 1.5 to 12 years of age and found that in children who can walk independently, those who were shorter and/or lighter tended to also have lower gross motor skills than same aged peers. It is important to monitor growth in children with CP and get timely help with feeding and nutrition.

Interdisciplinary intervention for children with feeding and swallowing disorders: the role of speech and language therapists and dietetians

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Introduction: Children with neurological impairments are at high risk for feeding and swallowing disorders (FSD), malnutrition and other accompanying problems. Due to complexity of FSD an interdisciplinary team is needed to provide an individual specific assessment and intervention, in which a speech and language therapists (SLT) and dietitians have an important role.

Patients and Methods: 72 children with neurological impairment from the age of 6 months and 15.2 years were included. All were evaluated by SLT who decided for further assessment and intervention, if needed, and a dietitian who provided nutritional assessment intervention (anamnesis, anthropometry, body composition measurement, nutritional diary analysis).

Results: SLT recognized feeding problems in 53 (73.6%) children, while the dietitian recognized feeding and nutrition problems in 55 (76.4%) children. There was a statistically important correlation (p<0,001) between identified children by SLT and the dietitian. Almost half (43.1%) of the children were fed by a nasogastric tube or gastrostomy. More than half (55.6%) received oral nutritional supplements (ONS) or enteral formulae. Feeding therapy program mainly targeted sensory-motor feeding problems (27.8%) and development of oral-motor feeding skills (19.4%). Nutritional intervention most frequently included prescribing or adjusting ONS (34.7%), counselling (29.2%) and adjusting enteral nutrition plan (19.4%).

Conclusion: The results strongly support the need for a systematic collaboration of SLT and dietitian in FSD and malnutrition intervention. As children with FSD often lack the energy and nutritional intake, the interdisciplinary intervention of both SLT and dietitian working closely together is crucial for a positive outcome.

Relevance for users and families: A systematic collaboration of SLT and dietitian could provide a more comprehensive approach to the care of children with feeding and swallowing disorders and/or malnutrition. This would provide a better outcome for children and their families.

The feeding tube weaning program: a first case report of treatment approach in Slovenia

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Introduction: Several factors contribute to development of feeding difficulties to such an extent, that child needs feeding tube (FT) and later develops dependency on it. Multidisciplinary approach, a supportive environment for parents and a precise plan of actions are needed for FT weaning program. We present a case of a child, who was dependant on FT for 5 years after intensive medical care due to intestinal inflammation at the age of nine months.

Methods and patients: Child was born prematurely, sensory sensitive, with less mature attention and specific problems in communication. With 16 months she was referred to sensory oral stimulation program due to aversive feeding behaviour. Despite of progress in accepting different flavours and food structures, she was not willing to resume oral feeding. The multidisciplinary team planned and executed intensive, 3 weeks long inpatient tube weaning program of four phases – evaluation, hunger induction, therapy program with individual goals and the follow-up phase.

Results: The child developed positive attitudes towards oral intake of food and drinks. By reducing the caloric intake via FT, alleviating the emotional anxiety related to oral feeding play activities, and allowing the child to "lead" in feeding situations, the child managed to completely transfer to oral feeding. No medical complications or adversities arose in that time, nor at the follow-up after three, six and 12 months.

Conclusion: Step-by-step multidisciplinary team approach in FT weaning program was efficient and safe. The child was able to fully transfer to oral feeding and retained it at follow-up.

Relevance for users and families:

Step-by-step multidisciplinary team approach to help children in feeding tube weaning program is efficient and safe.

Profile and needs of rehabilitation services of patients in pediatric palliative care

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Introduction: Pediatric Palliative Care Units (PPCU) play a fundamental role in the care of patients with very serious life-threatening pathologies.

In our hospital, PPCU was created in May 2017 and has been growing exponentially until today. The aim of this work is to recognize the profile of patients in PCCU who are also treated in the Pediatric Rehabilitation Unit (PRU) and to know their needs in this area.

Methods: We have studied all patients treated at the PCCU from 2017 until today. We have determined the percentage of patients who are also treated in PRU from three spheres (motor, respiratory and speech areas).

Results: From 171 patients treated in PCCU, 59.1% corresponded to cerebral palsy (87% GMFCS V), with a mean age of 8 (range 0 – 28).

From them, 139 (81.2%) have required Rehabilitation care. In 51% of the cases, that has been offered from the 3 spheres, in 37.3% from 2 of them and in the rest (11.7%), only from one of them.

A follow-up of the process was carried out on all patients, whether it was control of orthopedic deformities or respiratory or speech evaluations. In 21.5% of cases, a therapeutic approach was performed for pain, in 48.2% some type of orthoprosthetic article was prescribed and in up to 95.6% of cases some type of rehabilitation treatment was managed.

Conclusions: Patients with serious potentially disabling pathologies controlled in PPCU require comprehensive rehabilitation care, which ensures the acquisition of maximum functionality and quality of life.

Relevance for users and families:

The multidisciplinary approach to patients with disabilities facilitates care and avoids delays in the **Introduction** of therapeutic interventions.

Children's Hospice services; Care processes and Family Satisfaction.

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Introduction: Children's hospices provide a range of supports to children with life-limiting conditions and their families. The lack of research examining family caregiver's satisfaction with children's hospice services is prominent.

Service evaluation is important to inform the further development of services in palliative care. This study aimed to assess from the perspective of parents/caregivers the degree of family-centred care and level of satisfaction with hospice services.

Patients and Method: The study adopted a general repeated cross-sectional survey design using a self-report online survey. Participants were 28 active parents/caregivers recruited via email contact.

Measures included:

- Measure of process of care (MPOC-20)
- Client satisfaction survey (CSQ)
- Service use question: parents were asked to identify the specific aspects of hospice service used.
- Appreciative Enquiry; 3 open-ended questions about what is working well in the hospice, opportunities for development, and overall experience of research participation.

Results: Arithmetic mean of CSQ indicates high satisfaction with the service. The care is perceived as family-centred to a moderate to high extent. CSQ correlated positively with MPOC in several sub-scales, ie perception of family centredness is associated with greater service satisfaction.

Thematic analysis of the appreciative enquiry showed that families find care compassionate, family-centred, responsive and demonstrated the benefit of short stays.

Conclusion: This study demonstrates the relationship between delivering family-oriented care to children with complex needs and their families and parents'/caregivers' satisfaction with provided services. Parents/caregivers offer insightful suggestions for further development of services in palliative care and importance of research participation.

Relevance for users and families:

This study invited parents/caregivers to give their opinion regarding the family-centredness of service, express satisfaction with service provided and to offer areas for improvement. This parent input is essential to allow ongoing service improvement .

Netherlands CP register for children with cerebral palsy: An innovative model for personalized care with patient participation

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Introduction: The Netherlands CP register is an innovative follow up and treatment register for children and adolescents with cerebral palsy (CP). The register is developed in a unique collaboration between children with CP and their parents, patients' association (CP Nederland), researchers and a multidisciplinary team of health care professionals. The register aims to provide personalized and meaningful care for children with CP throughout The Netherlands.

Methods: The registry assists in early detection of (secondary) problems, using a traffic light system, and timely intervention. Moreover, in the register standardized outcome measures are collected for interventions including patient-reported outcome measures of activities and participation. The use of Goal Attainment Scaling supports active participation of children, their parents and professionals in shared goal setting. By collecting real life data from both professionals and patients we gain knowledge about (long term) development and effects of interventions on meaningful outcomes. On the basis of data aggregates, we will be able to predict which intervention is most effective for whom.

Results: The register is currently implemented in 14 rehabilitation centers and hospitals throughout The Netherlands. More than 200 children with CP are included in the register. Pediatric physiatrists and pediatric orthopedic surgeons integrate the register in their daily care to monitor the childrens' development and to evaluate interventions.

Conclusion: This national CP register involving all stakeholders, contributes to improvements in the quality of care for children with CP on both the individual and national level.

Relevance for users and families:

The Netherlands CP register monitors the development of the individual child and assists in early detection of (secondary) problems, allowing timely intervention and preventing secondary problems. Moreover, the use of patient-reported outcome measures and Goal Attainment Scaling leads to shared decision making and meaningful care for children and their parents.

Social workers' ASD knowledge and clinical self-efficacy regarding autism diagnosis and interventions: The role of professional background

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Introduction: Children with autism spectrum disorder (ASD) are often diagnosed at a later age and thus have limited opportunities to benefit from early intervention. Early detection depends upon competent community providers. Social workers are well positioned to detect ASD, especially in disadvantaged populations. This study assessed social workers' ASD knowledge and clinical self-efficacy in ASD care.

Methods: Social workers (N = 229; M = 13.97 years of experience; SD = 8.59) completed the ASD Knowledge and Self-Efficacy Questionnaire (Atun-Einy & Ben-Sasson, 2018) and a demographic and professional background questionnaire.

Results: Social workers displayed a high level of knowledge regarding ASD etiology and interventions (M = 5.01, SD = 0.38 Scale 1–6) and a low average rate of declaration of a lack of ASD knowledge (M = 9.4, SD = 9.2). On Average, they answered 58% of the questions regarding ASD core symptoms correctly (SD = 12.11). Working in multi-professional teams positively predicted their knowledge of ASD core symptoms. Using multiple regression analysis, self-efficacy was positively predicted by all knowledge parameters.

Conclusions: A multidisciplinary approach enhances social workers' ASD diagnostic knowledge and clinical self-efficacy, enabling them to face current detection and treatment challenges.

Relevance for users and families:

Social workers are well positioned to detect ASD, especially in disadvantaged populations. This study assess their knowledge and clinical self-efficacy in ASD care.

Taking Bladders Into Our Own Hands: A Pilot Rehabilitation-Led Paediatric Urodynamics Service

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Introduction: International guidelines for management of neurogenic bladder in congenital spinal dysraphism recommend regular urodynamic studies over the first few years of life and as needed thereafter to guide changes in clinical management. Access to urodynamic studies has been limited at our centre due to low availability of trained personnel. In order to address the unmet clinical need for urodynamic studies in our spinal dysraphism population, we have developed a urodynamics service within our paediatric rehabilitation department. This is the first service of its kind in Australia.

Patients and methods: We will present our novel approach to providing urodynamic assessment in a multidisciplinary rehabilitation clinic setting involving medical, nursing, child life therapy and psychology clinicians. We will present a case series of 12 studies performed during our first year of operation in children aged 9 months-17 years.

Results: All 12 studies were performed successfully, with good procedural tolerance and high patient and family satisfaction. These studies were performed in a timely manner, which could not have been offered by our local tertiary hospital. Our procedural environment was preferred by families over the hospital as a less intimidating clinical space. Appropriate interventions were able to be implemented immediately following each study.

Conclusion: A rehabilitation-led urodynamics service is an effective, efficient and highly acceptable way to provide timely urodynamic studies for children with spinal dysraphism. This service model should be considered for broader implementation.

Relevance for users and families:

Our urodynamics service patients and families expressed a high degree of satisfaction with having their studies performed by our service rather than through the local tertiary hospital. this service model has potential to directly improve patient and family experience of an invasive investigation.

Using the Integrated Knowledge to Action framework to implement the early detection guidelines for cerebral palsy and investigation of social determinants of health in a Western Australian early intervention service

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Introduction: Knowledge Translation (KT) strategies were used to implement the early detection guidelines for cerebral palsy (CP) in a state-wide tertiary early intervention (EI) service. We also investigated the association between social determinants of health, adverse childhood experiences (ACEs) and service access.

Patients and methods: KT strategies including consumer perspectives, clinician training and communities of practice (CoP) guided implementation. We measured change in referral numbers and age, delivery of early detection and intervention. Exposure to ACEs, appointment non-attendance (DNA) rates, remoteness and socioeconomic quintiles were used to measure social determinants of health using negative binomial (Incidence Rate Ratios, IRR) and logistic regression (Odds Ratios, OR).

Results: Interim Results to 2020 show 10 consumers participated in Focus Groups, 100 clinicians were trained and 22 established a monthly CoP. Referrals increased four-fold to 511 children. Corrected gestational age at referral decreased from a median of 16.1 to 5.1 months ($p<0.001$) and at first appointment from 18.8 to 6.8 months ($p<0.001$). Children living in social disadvantage had the highest DNA risk (quintile 1 vs 5: IRR 2.2, 95% CI 1.1 to 4.6 $p=0.037$). Children exposed to ACEs had higher odds of living in social disadvantage (Quintile 1 vs 5, OR=3.8, 95% CI 1.4 to 10.0, $p=0.007$). No significant association was found for remoteness with DNA rate or ACE score.

Conclusion: Implementation strategies reduced referral age and improved delivery of early detection assessments. Further investigation of association between social disadvantage, DNA risk and ACEs will guide development of a state-wide early detection network.

Relevance for users and families:

This study demonstrated the effectiveness of using the Integrated Knowledge to Action framework to implement the guidelines for early detection of cerebral palsy in a state-wide early intervention service. Investigation is continuing to determine whether it is possible to improve health outcomes for all children in Western Australia, especially those living in relative social disadvantage, with targeted training and support to improve access and engagement in early intervention services.

Establishing agreement on acceptable and effective services and core provision in future emergencies for disabled children

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Introduction: The COVID-19 pandemic brought unprecedented challenges for the delivery of care. Non-essential services were paused and restarted but often in a different way, usually online. We aimed to seek consensus between families, professionals and commissioners on acceptable and effective organisation and delivery of care in future emergencies.

Patients and Methods: Recommendations for delivery of care to disabled children in times of emergency were drafted from a literature review, interviews with parent carers (n=46) and professionals working in health, education and social care (n=78). These were further developed in six focus groups (3 for professionals, 2 for parents, 1 mixed). Parent carers, young people and professional from health, education and social care were invited to take part in a national Delphi survey to rate the importance of the recommendations over two rounds. Following this, online meetings were held to seek consensus on the importance of the recommendations.

Results: Following the focus groups, 28 recommendations for planning services for a future emergency were included in the Delphi survey. The survey invitation was sent to 291 parent carers, 214 professionals and seven young people who registered on the study website. We will present consensus on the most critical recommendations for core service provision in future emergencies.

Conclusions: A nationally agreed set of recommendations on provision of services for disabled children has been developed. Adoption of these recommendations should reduce the negative impact of emergency service restrictions on disabled children and young people and their families in future emergencies.

Relevance for users and families:

The Results provide an agreed set of recommendations for how services should be provided in a future emergency. Adopting these recommendations should reduce the impact of necessary reductions to services on disabled children and their families. The recommendations outline what essential provision needs to continue and what support needs in to be in place for families in times of emergency.

Increasing evidence uptake in children's occupational therapy by applying the i-change model and consolidated framework of implementation research (CFIR).

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Introduction: Although there is high-quality research available that recommends certain therapeutic approaches in children's occupational therapy (OT), the knowledge-to-practice gap persists. This has significant implications on therapeutic effectiveness, which is critical for the life trajectory of young consumers. The aim of this research is to explore current evidence-based practice (EBP) uptake amongst children's OT's, and to identify the key influences on practice using the Consolidated Framework for Implementation Research (CFIR) and I-change socio-cognitive behavior change model.

Materials and Methods: A cross-sectional mixed Methods approach was applied across five public health services in England. Children's OT's were recruited through convenience sampling. Data was gathered through file audits and self-reported behaviour questionnaires to determine current practice. Focus groups and a knowledge quiz were completed with these same OTs to determine barriers and facilitators to implementing EBP. Qualitative data will be abductively coded into the I-change and CFIR models. Individual participant audit scores will be aggregated, with participants to be categorised as either 'more frequently engaging in EBP' (total score ≥ 50%) or 'less frequently engaging in EBP' (total score ≤ 49%). Spearmans rank order correlation will be used to determine the strength and direction of the relationship between self-reported EBP behaviour and file audit outcomes.

Results: Analyses is currently underway, and full Results will be presented at the time of the conference.

Conclusion: Results of this study will guide a targeted knowledge translation strategy to improve evidence use in practice amongst children's OT's.

Relevance for users and families:

Knowledge translation aims to improve evidence based practice uptake. Evidence based practice is associated with multiple benefits, including enhanced treatment outcomes, increased clinician job satisfaction and reduced burnout, increased service delivery efficiency and increased equity to service access. This research contributes to implementation science research, bridging the evidence to practice gap for young people accessing service and their families.

Improving continence of children and young people with neurodisability: what are people doing and is there any evidence it is effective?

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Introduction: Children and young people with neurodisability often need help to achieve continence. Currently there is uncertainty about which interventions are effective. This study aimed to summarise evidence and practice for improving continence for children and young people with neurodisability.

Patients and Methods: A needs-led conceptual framework co-produced with stakeholders informed the research. We conducted national online surveys with health professionals, parent carers, young people and school and care staff. We conducted a systematic review of studies evaluating the effectiveness, cost-effectiveness or implementation.

Results: In total 949 people responded to the survey including 202 health professionals, 605 parent carers, 122 school and social care staff, and 20 young people. The survey Results illustrated the different roles that professionals have in improving continence, highlighting the importance of a multidisciplinary approach to supporting children and young people and their families. Clinicians employ a range of assessments and interventions to improve continence or independent toileting, depending on the needs of the child. Most evidence was for children with spinal cord pathology and involved evaluations of pharmacological approaches and surgical techniques; those for non-spinal cord pathology evaluated behavioural interventions. We found substantial heterogeneity across the interventions we evaluated in terms of study design and outcomes measured.

Conclusion: We recommend better training for health and care professionals about toileting. We recommend joined-up multidisciplinary and holistic approach to improving continence to maximise independence, dignity and comfort.

Relevance for users and families:

It is vital that children with neurodisability have early access to regular, integrated assessment of their bladder and bowel health, and are supported with personalised treatment.

An evaluation of the Ei SMART training programme in a neonatal operational delivery network in the UK

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Introduction: Despite advances in neonatal care, preterm and term-born infants remain at risk of neurodevelopmental challenges. Early intervention (Ei) is recommended however, specific Ei training is not widely available. Quality improvement programmes are required to evaluate Ei training. Ei SMART is an evidence-based approach to optimise developmental outcomes that spans infant development from birth, to pre-school and beyond. It uniquely supports infant development by integrating Sensory, Motor, Attention and regulation and Relational development through co-production between multi-disciplinary healthcare professionals and parents working Together. Aim: To evaluate participant learning following Ei SMART training.

Methods: A face-to-face Ei SMART training programme, co-produced and co-presented by parents and healthcare practitioners was delivered to 34 staff members from one UK neonatal operational delivery network via taught online modules and tutorials. Participants completed a survey adapted from Westrup et al (2002) and Warren et al (2019) pre and post training. Survey questions quantified self-perceived understanding of Infant Development & Well-Being, Parent/Family support and Engagement and Staff Engagement & Well-Being. Total scores and sub-scores in each domain were compared pre and post training using Student's t-test.

Results: 33/34 (97%) participants completed both pre and post-training surveys. One participant had incomplete responses and was excluded from the analysis. The mean total post-training score was significantly higher than the pre-training score (153 v112) ($p<0.001$). Mean post-training sub-scores were also significantly higher in each domain.

Conclusion: The Ei SMART training programme provided measurable improvements in learning for NICU clinicians to support timely provision of early intervention.

Relevance for users and families:

Ei SMART training is effective in improving clinical learning across the domains of Infant Development & Well-being, Family support & Engagement and Staff Well-being and Engagement.

Ei SMART provides a framework to implement the principles of co-production between parents and clinicians in training delivery and application in practice. These core relational values are a primary reason for its potential to support timely, effective delivery of family-integrated developmental care to optimise neurodevelopmental outcomes for high-risk infants.

Survey of current practice of routine neurodevelopmental follow-up in UK neonatal services

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Introduction: Given the high risk of adverse health, developmental and educational outcomes for children born very preterm and those with brain injury at birth, neonatal follow-up is crucial for the early identification of developmental problems and timely provision of intervention. An understanding of the variation in current practice is needed to inform quality improvement.

Methods: The weblink to an online survey was emailed to the lead clinician for follow-up in all neonatal units in the UK (n=187). Respondents answered questions about the structure of their follow-up service, inclusion criteria, assessment tools and measures, timing, communication, information management, and the impact of covid-19. Respondents provided consent for data sharing and reporting of Results.

Results: Eligible responses were received from 154 neonatal units (82%). This included 52/58 (89%) NICUs, 68/86 (79%) LNUs, and 34/43 (79%) SCBUs. Overall, 136 units (88%) offered neurodevelopmental follow-up for infants born <30 weeks' gestation and 75 (51%) for infants born <32 weeks' gestation. Out of 145 responses, 134 units (92%) offered follow-up to infants with brain injury requiring cooling therapy. The General Movements Assessment was used by 32 units (22%), PARCA-R questionnaire by 52 (35%) and Bayley-III by 80 (55%). A 2-year neurodevelopmental face-to-face appointment was offered to infants born <30 weeks' gestation by 129 units (83%); only ten units (6%) offered a 4-year assessment for infants born <28 weeks' gestation.

Conclusion: There is wide variation in the structure and content of neonatal neurodevelopmental follow-up. Greater standardisation of follow-up services is needed to reduce inequalities in care.

Relevance for users and families:

Infants born preterm or suffering brain injury at birth (and their families) should receive equitable neonatal neurodevelopmental follow-up which fulfils recommended clinical guidelines. This survey describes variation in the current UK service provision for neurodevelopmental follow-up.

Improving access to early intervention for infants at high risk of cerebral palsy - a quality improvement project

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Introduction: Enable Ireland Kildare operates a regional specialist motor service which supports local disability teams in providing evidence based timely intervention to children with primary motor disorders, including cerebral palsy (CP). An audit of infant referrals in 2019 showed that of 11 referrals, 5 were referred at >6 months old, 6 referred at > 1 year. This meant the window for early detection and intervention for CP was missed.

Patients and Methods: a quality improvement (QI) project was undertaken. Process mapping was completed for the 2019 referrals and key points contributing to delayed referral and uptake identified. A series of PDSA cycles were completed to challenge and improve these processes.

Results: key problem areas were poor awareness of the service among referrers, ineffective screening of referrals to local services where local service did not identify need for specialist motor team, administrative delays in securing parental consent at the point of referral receipt. Simple steps were taken to address each area with immediate improvement in referral patterns and service access.

Conclusion: a simple QI initiative successfully addressed barriers to efficient referral to early intervention for infants with or at risk of CP.

Relevance for users and families:

This initiative is relevant to infants who will benefit from early diagnosis and intervention, and to families seeking appropriate information and guidance. It is known families experience greater stress where diagnosis of CP is delayed. The benefits of early, targeted, goal oriented intervention are well established. This work improved the experience of families, provided a more helpful framework for referrers and a more positive therapeutic relationship between the family and treating team.

Physical activity participation in adolescents with autism spectrum disorder: barriers and facilitators – a qualitative study

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Introduction: Research shows that adolescents with autism spectrum disorder (ASD) participate less in physical activity (PA) compared to their typically developing peers. Considering the health benefits of PA in this population, it is crucial to understand the barriers and facilitators adolescents with ASD experience with regard to PA participation. However, literature concerning this topic is scarce. Therefore, the purpose of this qualitative study was to examine the barriers and facilitators adolescents with ASD experience with regard to PA participation in three specific PA contexts (i.e. PA participation in unorganized PA, in a sports club, and during physical education classes).

Patients and Methods: In total, 17 adolescents with ASD (n = 11 boys, 14.4 ± 1.6 years) participated in this qualitative study. Semi-structured interviews were performed to collect the barriers and facilitators adolescents with ASD experience with regard to PA participation in the three different PA contexts, based on the principles of the socio-ecological framework. Data analysis was conducted with Nvivo 12 software and both deductive and inductive content analysis were applied.

Results: Barriers and facilitators of PA participation at all levels (i.e. intrapersonal, interpersonal, environmental and policy level) of the socio-ecological framework in all three PA contexts were reported. Barriers and facilitators related to ASD symptomatology and the specific PA context were also found.

Conclusion: Adolescents with ASD experience a variety of intrapersonal, interpersonal, environmental and policy barriers and facilitators with regard to PA participation. These barriers and facilitators can be context and ASD-specific.

Relevance for users and families:

The Results of this qualitative study help to better understand the role, meanings and processes that influence physical activity participation in adolescents with autism spectrum disorder (ASD) in three specific physical activity (PA) contexts. In addition, these Results may provide important information to guide the design of new evidence-based and context-specific PA interventions to facilitate the adoption of a more active lifestyle in adolescents with ASD.

Community-based physical activity interventions for adolescents and adults with complex cerebral palsy: a scoping review investigating implementation and safety

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Introduction: Adults with complex cerebral palsy (CP) are at high risk of chronic health conditions that could be ameliorated by increased physical activity, however, some express concern about participation in physical activity due to fear of pain, fatigue or unspecified 'risk'. Others express a desire to move away from engaging with therapy interventions in a clinical environment. This scoping review aimed to identify implementation strategies and safety outcomes (adverse events) of community-based physical activity interventions for adolescents and adults with complex CP.

Patients and Methods: Five electronic databases were systematically searched to April 2022. Data were extracted on the implementation and safety of physical activity interventions for adolescents and adults with CP, GMFCS IV and V, delivered in a community setting.

Results: Seventeen studies with 262 participants (160 participants GMFCS IV or V) were included. Community settings included schools (n=4), participants' homes (n=3), gymnasia (n=2), swimming pools (n=2) and other settings (n=4). Most studies specified medical or safety exclusion criteria. Implementation strategies included pre-exercise screening, use of adapted equipment, familiarisation sessions, supervision, physical assistance, and physiological monitoring. Attendance was high and attrition low. Nine studies reported non-serious adverse events such as minor soreness and fatigue after exercise. Serious adverse events related to exercise were infrequent (n=5) and related to pain requiring temporary exercise cessation or program change (n=3), or study withdrawal (2 participants).

Conclusion: For most adolescents and adults with complex CP at GMFCS Level IV and V, community-based physical activity interventions can be safely performed without serious adverse events.

Relevance for users and families:

Relevance for users and families: For most adolescents and adults with complex cerebral palsy (GMFCS IV and V), participation in physical activities within the community is both safe and feasible, facilitated by strategies such as supervision, physical assistance or heart rate monitoring. The findings of this review support the capacity of people with more complex CP to participate in community-based physical activity across different modes and in a variety of community venues.

The effects of community-based physical activity interventions on adolescents and young adults with disability: A systematic review and meta-analyses of randomised controlled trials

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Introduction: Young people with disabilities want to exercise in the community, like their peers. This systematic review evaluated the effects of participation in community-based, structured, physical activity interventions for young people with disabilities, across all domains of the International Classification of Functioning, Disability and Health (ICF).

Methods: Nine databases were systematically searched. Data were synthesised descriptively, and outcome measures mapped against the ICF. Random-effect meta-analyses were performed to calculate mean difference and 95% confidence intervals (95% CI).

Results: Thirteen trials (n=396 participants) were included. Interventions took place across a variety of community settings; 48 unique outcome measures identified. When mapped to the ICF, measures assessed body structure and function (k= 23), activity (k= 18) or contextual factors (k= 5). There were no measures of participation. Eleven trials contributed to the meta-analysis. Community-based physical activity had positive effects on upper body strength (mean difference 8.9kg, 95% CI 2.3 to 15.5, I2 = 31%), lower body strength (mean difference 23.5kg, 95% CI 13.1 to 33.8, I2 = 0%), waist circumference (mean difference -5.2cm, 95% CI -10.1 to -0.4, I2 = 0%), stair climbing (mean difference -4.0 secs, 95% CI -7.4 to -0.7, I2 = 0%), and box stacking activities (mean difference 2.4 boxes, 95% CI 0.1 to 4.8, I2 = 0%) compared to a control group immediately after the intervention.

Conclusion: Community-based physical activity interventions improved muscle strength, functional activities, and reduced waist circumference for young people with disabilities. Future studies should evaluate participation outcomes, to align with priorities of young people.

Relevance for users and families:

Participating in physical activity programs within the community can lead to increased arm and leg strength, smaller waist measurements, quicker stair climbing, and better performance of functional tasks for young people with disabilities. The findings of this review support the preferences of young people with disabilities to participate in community-based physical activities, within settings that match their interests.

Physical activity engagement in children with cerebral palsy: Physiotherapist and adapted sports provider's perspectives. A qualitative study

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Introduction: Despite the clear benefits of physical activity (PA) participation in children with cerebral palsy (CwCP), their engagement remains low. An array of qualitative research has addressed barriers and facilitators as perceived by CwCP and their families, yet not much focus has been placed on the perspectives of clinicians working with this cohort. This study therefore explored their views.

Methods: Seven semi-structured interviews were conducted with four physiotherapists and three adapted sports providers, at which stage data saturation was achieved. All interviews were recorded and transcribed using MS Teams. Thematic analysis of the transcripts was conducted by the first author and checked for agreement by the second author. A focus group with 4 participants was subsequently held, to conduct member checking and confirm data saturation.

Results: Four key themes were identified: (1) The environment and local community, (2) Child-related factors, (3) Role of the professional, and (4) Parental/family impacts. Barriers within these themes included having to travel large distances for PA, self-consciousness/lack of confidence, fears around safety in teachers/facilitating staff and parental lack of time, respectively. Facilitators included accessible facilities, making friends, staff supporting sustainability of PA and parents engaging/sharing information amongst themselves, respectively.

Conclusion: Enquiring the previously underexplored views of physiotherapists and adapted sports providers contributed to establishing a more complete knowledge base on this topic. Their views reiterated what CwCP and parents have reported previously, with the addition of factors which they have identified in their practice, some novel, namely the impacts of the COVID-19 pandemic.

Relevance for users and families:

The findings of this study may be of significant benefit to children with cerebral palsy (CwCP) and their families, by contributing to a more complete knowledge base to inform future physical activity (PA) provision for these children, to ultimately increase their PA engagement, leading to better health outcomes. The identified barriers can be addressed, and the facilitators augmented when implementing policy and planning future PA provision.

Changes in Foot Posture Over the Course of Childhood in Ambulatory Youth with Cerebral Palsy

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Introduction: The purpose of this study is to evaluate the evolution of dynamic foot posture in ambulatory children with CP.

Patients and Methods: Children with CP, aged 17-40 months, were recruited to participate in this IRB approved prospective longitudinal study. Dynamic foot posture was measured during walking by coronal plane pressure index (CPPI) and foot segment impulses from age 2-21 years. Data were compared between children with CP stratified by GMFCS and typically developing (TD) children utilizing lossless averaging and serial Welch's t-tests across time with Holm correction for multiple comparisons.

Results: 33 children (21 bilateral and 12 unilateral; GMFCS: I(13), II(14), III(4), IV(2)) were included in the analysis. Children completed 16.9 (± 4.4) evaluations between age 2.9 (± 0.7) and 18.6 (± 1.7) years. 525 evaluations were compared with 862 age matched evaluations of TD children. Among 65 total surgeries, 39 procedures were performed to address foot deformities: 11 to address varus, and 28 to address valgus. Children with CP begin walking with valgus and those classified as GMFCS I/II tend to normalize with growth while those at GMFCS level III/IV tend to persist until surgical intervention (Figure; $p<0.05$). Reduced heel pressure is initially present among all GMFCS levels ($p<0.05$) but improves with age in children at GMFCS levels I-III.

Conclusion: Young children with CP walk with valgus foot posture and limited heel contact which tends to resolve with growth in those walking without an assistive device. Conservative management is recommended in early childhood with close monitoring throughout growth.

Relevance for users and families:

The description of deformity management and foot posture progression can be utilized to guide treatment and educate families on expected outcomes.

Pre-operative Psychosocial Assessment in Pediatric Patients with Cerebral Palsy Decreases Length of Stay after Spine Fusion

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Introduction: Caregivers of children with cerebral palsy (CP) experience significant stress surrounding orthopedic surgery. A pre-operative psychosocial assessment (PSA) can help identify stress risk factors and connect caregivers with resources. This study examined the relationship between a pre-operative PSA and hospital length of stay (LOS) for children with CP who underwent spine fusion (PSF).

Patients and Methods: Forty-six patients undergoing PSF who met inclusion criteria (diagnosis of CP and GMFCS IV or V) and had a pre-op PSA were matched by age, sex, race, GMFCS level, and severity of neurological impairment to a group without pre-op PSA. Pre-op PSAs by a social worker included evaluation of family support, financial needs, transportation, equipment, housing, therapy, etc. Mann-Whitney and Chi-squared analyses were used to examine differences between the matched groups. A stepwise linear regression was run to identify which factors influenced hospital LOS. Statistical significance was set at $p \leq 0.05$.

Results: The matched groups of 46 patients (with/without PSA) had no significant differences in age (10.8y/11.2y) sex (M 28/21) (F18/25), race (Caucasian 28/28, African American 13/13, Other 5/5), and GMFCS level (IV 17/16, V 29/30). Pre-op PSA tended to significantly decrease LOS ($p=0.000228$), 7 days compared to 12.5 without PSA.

Conclusion: Completion of a pre-op PSA for youth with CP was associated with a significantly decreased hospital LOS in patients who underwent spine fusion. Findings suggest that the clinical practice of identifying and addressing psychosocial needs of youth with CP and their families prior to orthopedic surgery can lead to more timely discharge.

Relevance for users and families:

Families with children with cerebral palsy face increased psychosocial stresses, that increase around the time of major interventions like surgery. A preoperative biopsychosocial assessment by a social worker can help in that stressful period and make hospital stays easier.

Aims and Outcomes in Secondary Shoulder Surgeries in Neonatal Brachial Plexus Birth Palsy Patients: A Scoping Review

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Introduction: Neonatal brachial plexus birth palsy (NBPP) refers to injury to the brachial plexus at birth. This study aims to summarize the type of secondary surgeries performed to repair shoulder deficits, their post-surgical outcomes, and aims.

Patients and Methods: Following PRISMA-ScR guidelines, searches of PubMed, Cochrane, CINAHL, Web of Sciences, and Scopus were completed to identify articles related to secondary procedures for NBPP. Inclusion criteria were studies including pediatric NBPP patients who underwent a secondary surgery for shoulder deficits. Data points extracted included motion outcomes and scoring systems.

Results: 81 full-text articles with six main groups of procedures identified: osteotomy (14), release (16), muscle and tendon transfer (44), triangle tilt (7), botulinum toxin injection (3), and lengthening (7). The overall mean age of patients at time of surgery (n = 4309) was 6.1. The mean increase in active shoulder abduction was highest in release (48.7°), followed by muscle and tendon transfer (47.0°), lengthening (24.0°), and osteotomy (6.6°). The mean increase in Mallet score was highest in muscle and tendon transfer (5.1), followed by lengthening (5.1), triangle tilt (4.9), release (4.5), osteotomy (3.3), and botulinum toxin injection (0.9). Aims of these studies included: resolution of internal rotation contracture, restoration of external rotation and/or abduction, resolution of glenohumeral joint deformity, and shoulder stability.

Conclusion: All studies reported an improvement in function following the procedure. Mallet score was a homogenized tool for functional assessment across the literature. According to this measure, muscle and tendon transfer and lengthening displayed the greatest improvement in function.

Relevance for users and families:

This review assess the available procedures, how many studies exist discussing them for the pediatric population and what their aims include. This informs what procedures can be done if a patient is to present with the above deformities.

Tendoachilles tenotomy rate and timing in infants with idiopathic congenital talipes equinovarus in a quaternary children's health service

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Introduction: Optimal timing of tendoachilles tenotomy during Ponseti management of idiopathic Congenital Talipes Equinovarus (CTEV), is not clearly understood. This study aimed to quantify population-based tenotomy rate and timing, in relation to CTEV severity.

Patients and Methods: Clinical data was audited for 203 sequential infants with idiopathic CTEV (295 feet) receiving physiotherapy and/or surgical intervention between 2014-2021. Severity of CTEV was quantified by initial Pirani-Total and item scores, and Relative Reduction Ratio (RRR) (% change in Pirani-Total score between baseline and first cast Conclusion). Outcomes were tenotomy rate and timing (No tenotomy; Early: before brace commencement; Delayed: after commencement). Logistic regressions were calculated.

Results: Tenotomy rate was 53.5% (no=137, early=119, delayed=39). Compared to the no tenotomy group, the tenotomy group (early plus late) showed higher initial Pirani-Total scores ($p<0.001$) and higher item scores ($p<0.001$ to 0.003) except for curvature of the lateral border. Initial scores were not different between early and delayed subgroups. Feet with higher empty heel (EH) and lateral head of talus (LHT) item scores had higher odds of requiring tenotomy (OR(EH)=158.229, OR(LHT)=3.143). Multiple regression showed that initial EH and LHT scores together explained 26.6% of the variance in tenotomy requirement ($p(EH)<0.001$, $p(LHT)=0.011$). The RRR was lower in the tenotomy (40.8%) versus no tenotomy group (50%) ($p<0.001$), but not different between early and delayed subgroups.

Conclusions: Initial Pirani scores and RRR can identify infants needing tenotomy. However, many factors might influence eventual tenotomy timing. Future studies should involve long-term follow-up of casting/surgical intervention, functional outcomes and relapse risk.

Relevance for users and families:

Congenital talipes equinovarus may be associated with significant physical impairment and functional limitations, therefore early, effective intervention is essential. Casting with/without tendoachilles tenotomy is the current gold standard. However, this study provides the first population-based data for no/early/late tenotomy rates and objective baseline indicators for tenotomy. It also provides a new indicator, the RRR score, to assist clinicians to quickly identify children likely to need a tenotomy, which will assist parent counselling and surgical planning.

Neck of femur fractures in pediatric populations, a challenging and unfrequent disease

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Introduction: Hip fracture in pediatric patients is a rare injury. It means a challenge for the surgeon and the medical team, as it has a high complication rate despite correct diagnosis and treatment.

Patients and Methods: We present the case of a 4-year-old girl who presented with a Delbet type III neck of femur fracture. She was treated by closed reduction and internal fixation with three cannulated screws without penetrating the physis in order to avoid physeal arrest. A pelvipedic cast was needed to augment stability. A customization to our regular traction table was made for this purpose.

Results: The follow-up period was one year. The X-ray showed consolidation of the fracture and preservation of the femoral head without further anomalies. The bone fragility study showed loss of bone density. At the end of the follow-up, our patient had recovered all her previous functionality.

Conclusion: The outcome in these patients is usually poor. Complications in these patients are very frequent. Controversy about treatment continues to exist today. However, correct treatment in children with hip fractures can improve the prognosis. An early and multidisciplinary approach is necessary to obtain better Results.

Relevance for users and families:

Neck of femur fractures in pediatric population have an enormous impact on these patients. Secondary sequelae are very frequent. Improving the approach to this pathology is a challenge and a primary objective that lies in improving the functionality and quality of life of patients and their families.

The development of a stepped care psychology service for children with Severe Neurological Impairment.

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Statement of problem. Psychological support for parents of children with severe neurological impairment may be available informally, but for some parents, formal psychological support may be needed or wanted. However, there are few models available for determining how this support is best provided.

Description of the product or technology. A part-time (0.6 wte) psychologist was employed to support the families working with children with SNI. As the team already provide a high level of support a model of psychology involvement was needed to work alongside this. A model of stepped care was developed whereby all parents could have access to the psychologist in their clinic visits (universal access), but targeted support through topic-based group-work (targeted access), and individual support were also provided (individual access).

Findings to date. In the first 6 months of the service 30% of the children with SNI were seen by the psychologist at their routine outpatient hospital clinic appointment (n=24) or as an inpatient (n=2). Thirteen referrals for individual parental support were made, nearly half of which were offered within the outpatient clinic with the parent subsequently taking up the offer. Group sessions on managing sleep and working as a family were developed for role out in Spring 2023.

Practical applications. Offering a stepped care approach within a hospital setting may be an effective way of providing specialist psychological support. There was a high uptake of appointments offered by the psychologist at a routine medical appointment, as well as appropriate referrals made by clinicians.

Relevance for users and families:

A stepped care approach may be an effective and efficient way for parents to have access to psychological input within their child's routine hospital care. Some issues can be dealt with within routine appointments, and more significant issues can be picked up quickly and parents offered individual sessions. A stepped care model of psychological input may also make referral pathways smoother and may work well alongside the existing sources of support.

ENVISAGE-Families: qualitative findings of a program for caregivers raising children with neurodevelopmental disability

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Introduction: Raising a child with a neurodevelopmental disability creates unique challenges that can significantly impact the parenting experience. ENVISAGE (ENabling VISions and Growing Expectations) is a program co-designed by caregivers and researchers that aims to increase caregiver confidence and wellbeing. Caregivers are provided with current thinking about childhood disability, resources, and tools. This study explored caregivers' experiences of participating in ENVISAGE and reports the qualitative findings of the ENVISAGE-Families project.

Methods: Caregivers of a child with neurodevelopmental disability aged 6 years or younger were recruited across Australia and Canada. Caregivers participated in five weekly online workshops in small groups co-facilitated by a parent-partner and clinician-researcher. Interviews were conducted within 3 months of program completion. Data analysis was guided by interpretive description methodology. Quantitative data were also collected across 3 timepoints and are presented elsewhere (see Miller et al).

Results: All caregivers (n=65; 86% mothers) were interviewed. Caregivers' experience of ENVISAGE was interpreted through themes related to; why ENVISAGE was relevant, how ENVISAGE created time and space to reflect, and what changed for caregivers because of their participation in ENVISAGE. Caregiver perspectives shifted and/or were validated in how they viewed themselves, their situation, and their relationships within and beyond the family.

Conclusion: Caregivers of children with neurodevelopmental disabilities found ENVISAGE relevant to their needs. ENVISAGE can shift how caregivers think, feel and act in relation to parenting their child with neurodevelopmental disability.

Relevance for users and families:

ENVISAGE provides a conceptual guidebook for making sense of the experience of raising a child with a disability and encourages parents to do new things for themselves, with their child, their family and friends, and service providers.

The impact of the "ENabling VISions And Growing Expectations" (ENVISAGE) program for parents of children with developmental disabilities in Croatia: A discourse analysis study

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Introduction This study explored the impact of the 5-week online ENVISAGE program for parents of children with developmental disabilities (DD) on parents' perception of self, their child with a disability and their family in Croatia.

Methods This study followed a discourse analysis design. Participants took part in a semi-structured interview before participating in the program and were asked to attend five weekly Zoom group discussions. They were asked to participate in a post-workshop interview within one month post-program. The unit of analysis was sentences, where each sentence was first evaluated for its relevance and was given value as a negative, neutral or positive sentence. The proportions of positive, neutral and negative sentences about self, their child, and their family were compared from before to after ENVISAGE on an individual and group level.

Results Data from thirteen participants were included. We observed most changes in parents' perception of self (an average increase in positive views of 8.8% and a decrease in negative of 5.3%). The changes in perception of their child and family showed less variability, with the observed desirable changes for most categories (increase in positive and decrease in negative perceptions). The qualitative, self-expressed discourses of change also showed the most impact in the self domain, with less perceived impact on the views of the child and family.

Conclusions The Results support our assumption that ENVISAGE is a complex intervention with effects on multiple areas of life and functioning, particularly parents' views of self.

Relevance for users and families:

Reported impacts of ENVISAGE suggest that the program could be used for parent empowerment and other personal gains. The observed changes identified in this study will be considered in the future and guide further research exploration of the program's effects on parents of children with DD.

Therapy services for children and young people with Cerebral Palsy in low- and medium-income countries (LMICs)

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Introduction: United Nations reports that 80% of people with disabilities, including children or young people (CYP) live in low and middle-income countries (LMICs), although most of the disability research comes from high income countries. Understanding the circumstances of CYP with disabilities in LMICs, availability of therapy services and challenges experienced, can guide efforts to improve health and wellbeing. This study reports on therapy services accessed by CYP with Cerebral Palsy (CP) in LMICs.
Patients and Methods: Participants in the study (parents/carers of CYP with CP) answered 40 questions via Qualtrics, online questionnaire developed in collaboration with specialists in the field of childhood disability and parents of children with CP in LMICs.

Results: 152 Parents/guardians from 5 LMICs (India, Mexico, Romania, Bulgaria and Brazil) reported that only 22% of CYP accessed therapy provided by the National Health System, while the remaining used non-governmental organizations or private health providers. Half of the participants had difficulties with paying for therapy and travelling to/from therapy. The majority accessed Physiotherapy (82%), Speech and Language therapy (54%), Occupational Therapy (31%) though fewer accessed orthotics (7 %) or hydrotherapy. Only 32% reported that their child's hips were x-rayed and monitored. 9% attended mainstream school while the largest proportion attended special needs schools. 82% of parents had concerns about the child's activities of daily living.

Conclusion: The high proportion of CYP whose hips are not monitored is concerning. It is unclear whether parents of health professionals are aware of the importance of hip monitoring in CYP with CP.

Relevance for users and families:

Joint efforts from research and therapy service providers are needed to ensure hips examination as part of the health offer. More research is needed to understand the challenges of CYP with CP in LMICs especially since the lack of data from LMICs is often a barrier for securing funding for further research and interventions to improve the health and well-being of CYP in LMICs.

The assessment of grip strength and stereognosis in preschool-aged children with and without unilateral cerebral palsy.

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Introduction: Grip strength and stereognosis are major determinants of upper limb activity in children with unilateral cerebral palsy (uCP), and can be assessed reliably from five year onwards. In view of timely interventions, reliable and valid assessments are needed as early as possible. Hence, we investigated the reliability and validity of grip strength and stereognosis in children with and without uCP aged 2 to 6 years.

Patients and Methods: In 20 preschool-aged children with spastic uCP (mean age 4y±1y2m; 11 left-sided) and 20 age-matched typically developing children (TDC) (mean age 3y11m±1y3m), test-retest reliability and known-group validity of grip strength, using the Martin Vigorimeter and Myogrip, and stereognosis were investigated using intraclass correlation coefficients (ICC) and comparative statistics, respectively.

Results: Test-retest reliability was excellent for both grip strength devices and both hands (ICC 0.91-0.97). Test-retest reliability for stereognosis was moderate for the non-dominant hand (NDH) in children with uCP (ICC 0.62). For the dominant hand (DH) and TDC, ICC's were negative due to limited between and within-participants' variability. Grip strength was higher in the NDH of TDC compared to children with uCP for both devices ($p<0.001$). Moreover, grip strength ($p<0.001$) and stereognosis ($p=0.01$) were decreased in the NDH compared to the DH in children with uCP. In TDC, grip strength, assessed with the Myogrip ($p=0.02$), was lower in the NDH compared to the DH.

Conclusion: Both grip strength devices are reliable and valid to use in preschool-aged children with and without uCP. Further investigation is needed to reliably assess stereognosis.

Relevance for users and families:

Both the Martin Vigorimeter and Myogrip can be implemented in clinical practice to assess grip strength in preschool-aged children with uCP. Only the myogrip was able to detect differences between both hands in TDC, suggesting that this device might be more sensitive and better suited to detect subtle changes due to interventions or development.

Culture- and trauma-sensitive treatment of refugee toddlers and pre-schoolers – An interdisciplinary concept with a manualized parent group

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Introduction: In Germany 30 % of asylum applications were filed for children under the age of six in 2021. Young refugee children are affected by symptoms of trauma sequelae like fears, temper tamtrums and developmental delays which makes them vulnerable to later health and academic problems. Additionally, they are at risk for deprivation due to highly burdened parents.

Patients and Methods: We offer low-threshold multidisciplinary in-house therapeutic consultations for children, parents and caregivers and provide diagnostics and treatment with a focus on developmental aspects and trauma disorders. We foster a security-focused care within a clearly defined framework in child-care groups and the whole environment in the camp. The concept includes the binding work of parents within the "Parents' College", a culture- und trauma-sensitive psychoeducational group offer guided by a team of pediatricians, psychologists and therapists. Information on topics related to early childhood development and trauma sequelae is provided in four sessions in small discussion groups. The groups are held with interpreters as language brokers. The content is conveyed with image materials and adjusted to various cultural and educational backgrounds of the target group.

Discussion/Conclusion: Interdisciplinary cooperation is important for the early intervention in an integrated concept. It can help to reduce difficulties that arise within the health and educational context and thus minimizes long-term psychological and developmental vulnerability, chronification of existing symptoms and risk of retraumatization.

Relevance for users and families:

Difficulties can be assessed at an early stage. Parents can benefit from participating by gaining knowledge about topics related to early childhood development and trauma consequences in children, as well as health and educational conditions and options for therapy. The individual benefit for children is a secure, culture- and trauma-sensitive, child-friendly, and playful environment.

Probing changes in the brain's connectome following HABIT-ILE intervention- a pilot investigation

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Introduction: Recently, the Hand-Arm Bimanual Intensive Therapy Including Lower Extremities intervention has demonstrated feasibility as an early intensive intervention in pre-school children (1-4 years) with unilateral cerebral palsy (uCP). There is the potential for neuroplasticity induced by this intensive protocol to modify surviving structural networks, which we aim to observe using the structural connectome.

Patients and Methods: Children were recruited at three sites, Brussels (Belgium), Pisa (Italy) and Brest (France). A total of 9 children with uCP were included in this pilot randomized controlled trial (5 male, 1-4 years old). Magnetic resonance imaging were performed pre-therapy (T0) and 3 months post-therapy (T1) for the HABIT-ILE group; for the control group both T0 and T1 were performed during their conventional therapy. Structural and High Angular Resolution Diffusion-weighted Images were acquired. Connectomes were calculated using whole-brain probabilistic tractography with structural parcellation of the cortex and subcortical structures. Connections with altered fractional anisotropy (FA) in children undergoing treatment compared to controls were identified using network-based statistics.

Results: No significant changes in FA were observed between HABIT-ILE and control participants, however a non-significant increase in FA was observed in children undergoing HABIT-ILE at T1 versus T0 in several pathways, including corticospinal and thalamocortical pathways.

Conclusion/Relevance for users and families:

These initial findings support the observed functional changes in these children, with FA changes in the structural connectome induced by HABIT-ILE. Including further participants may elucidate the neurological correlates of improved function due to intervention.

Neonatal Therapeutic Hypothermia: Time to Achieving the Optimal Temperature, A National Perspective in Ireland 2019-2020

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Aims: To obtain the maximum benefit from Therapeutic Hypothermia(TH) the cooling process must be commenced by 6 hours of age.In Ireland,there are 19 maternity units/hospitals nationally, but just 4 tertiary/referral centres. This study was mounted to determine whether there were any differences between infants born in tertiary vs. local/regional maternity units,in reaching this target temperature range.

Methods: Data on TH cooling patterns for infants born in the tertiary NICUs and local/regional units was obtained from the 2019-2020 Neonatal Therapeutic Hypothermia national reports.We determined what proportion achieved the target temperature at 6hours.

Results: There were 147 TH cases: 98 infants were born in the 4 tertiary NICUs and 49 infants were born across the other 15 peripheral/regional units.The proportion of the TH infants reaching the target temperature by 6 hours in the tertiary NICUs was 92/98(94%).The corresponding proportion for the TH infants born in the peripheral/regional units was 36/49(73%)P<0.01

Conclusion: A greater proportion of infants born in the tertiary centres achieved the optimal temperature at 6 hours of age compared with the TH infants born in the local/regional units.In tertiary NICUs, the TH infants receive active cooling from the start.Infants in the local/regional units receive passive cooling at the start,with active cooling usually initiated when being transported by the National Neonatal Transport Programme.The findings would suggest that it would be preferable to commence active cooling from the start in the local/peripheral units, perhaps on a phased basis initially in centres with resources, training and where there is a Consultant Neonatology roster.

Relevance for users and families:

Therapeutic Hypothermia (TH) was rolled out as a national initiative in Ireland in 2009 and is now considered to be the standard of care for infants with moderate-to-severe Hypoxic Ischaemic Encephalopathy (HIE)/Neonatal Encephalopathy (NE), aiming to prevent long term sequalae. Although decision to cool is a national standard, where practice diverges is provision of active cooling being initiated immediately in tertiary centres, and we need to work to standardise this for our patients nationwide.

Characteristics of child directed behaviors during demonstration of new objects

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When demonstrating new knowledge to children, adults change and adapt their behavior. Adults form child-directed behaviors described as child-directed motions (motionese) and child-directed speech (motherese). These child-directed behaviors differ from the way an adult demonstrates objects to another adult.

The purpose of this study is to examine the characteristics of child-directed behaviors in mother-child interactions with children of different chronological ages.

The participants were mothers and children (N=15) aged 3-6, 7-9, 10-12, 18, and 24 months. The study was conducted in the child's home. The examiner presented the actions with the objects to the mothers and the mothers were instructed to repeat the actions and present a new objects to the child. In the warm-up phase, there was spontaneous interaction between the mother and the child. In the test phase, the mother randomly selected a task and presented the object to the child according to the instructions. All interactions were recorded on video and audio.

The Results show that the range of motion does not change depending on the age of the child. On the other hand, repetitiveness of movements decreases with age. Mothers in interaction with two-year-old children repeat the same movements the least and in interaction with children aged 3 months the most.

Analysis of motherese shows that the total number of words in the mother's speech is lowest in the 18-month age group. The Results shed light on the characteristics of child directed behavior that shape mother-infant interaction in knowledge transfer.

Relevance for users and families:

In successful interaction parents have sense of parent competence and children’s need to understand the world would be satisfied.

Inter-rater reliability for Slovene translation of the Writing Readiness Inventory Tool in Context (WRITIC) and writing readiness in a group of children with cerebral palsy

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Introduction: Writing Readiness Inventory Tool in Context (WRITIC) is a standardized, valid and reliable assessment instrument for typically developing pre-school children, recently translated into Slovene. Backtranslation to English proved semantic and conceptual equivalence. We wanted to check inter-rater reliability (IRR) of the Slovene translation and evaluate writing readiness in a group of children with cerebral palsy (CP).

Patients and Methods: The IRR study was done by three "blinded", WRITIC-licensed occupational therapist, evaluating 30 videos of children with CP across GMFCS levels (no. of I. to V. = 16/5/3/5/1), performing WRITIC tasks. IRR was assessed by Intraclass Correlation Coefficient (ICC(2.1)). Differences in average scores among raters were analyzed using ANOVA. Descriptive statistics were calculated for other data.

Results: IRR was absolute in the subscales »Child« and »Environment« (ICC=1), while for »Task performance« (TP) it was slightly lower, but still appropriate (ICC=0.85). IRR for »Performance Intensity« (PI) was slightly under the limit of being appropriate (ICC=0.79). Further analysis showed that scores assigned by one rater significantly differed from the other two (p=0.021, p=0.010) due to more gentle scoring. Analysis of achievements showed the mean TP and PI scores clearly decrease with higher GMFCS levels. The majority (70%) of children (mean age 8 years) were not ready for writing.

Conclusion: IRR was high enough to prove the reliability of Slovene translation of WRITIC, with suggestion to strictly follow the scoring criteria. The majority of children with CP were not able to develop sufficient writing skills long after they had entered the school program.

Relevance for users and families:

Relevance for users and families: A high consistency between evaluators is important to ensure relevant and reliable information for therapists, parents and teachers on writing readiness of pre-school children. Children with cerebral palsy have significant problems in writing readiness.

Intervention-refinement and feasibility of online delivery of the Healthy Parent Carers programme by Third Sector partner organisations

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Introduction: Parent carers of disabled children are at increased risk of physical and mental health problems, which can have implications for their ability to care for their children. The Healthy Parent Carers (HPC) is a peer-led group-based programme that aims to promote health and wellbeing and had been delivered in person in research. This study investigated the feasibility of implementation by Third Sector organisations and online delivery using Zoom.

Patients and Methods: An online delivery manual was co-created with parent carers and representatives from Third Sector organisations. Two Lead and two Assistant freelance facilitators were recruited by the organisations to deliver the programme to two groups of up to 16 parent carers. Stakeholders, including commissioners, parent carer forums, charity staff, and researchers, participated in a series of workshops to develop an Implementation Logic Model.

Results: Challenges were identified in terms of achieving independent implementation by Third Sector organisations, greater reach to large numbers of parent carers, identifying and retaining facilitators, and maintaining quality assurance. A co-developed Implementation Logic Model and implementation package were produced to enable wider roll-out of the programme.

Conclusion: This study found that it is feasible for partner organisations to deliver the HPC online in different geographical regions. Online delivery increases the programme's accessibility and sustainability by reaching more people expediently and less expensively. Further research is needed to evaluate the implementation model and cost-effectiveness.

Relevance for users and families:

Parent carers and Third Sector organisations were consulted throughout the study on research design, delivery and reporting. Healthy Parent Carers is the only peer-led group-based intervention solely designed to improve the health of parent carers, co-created by parents of disabled children for parents of disabled children. It has the potential to benefit huge numbers of parents of disabled children worldwide.

Early infant hypoglycaemia as sole cause of adverse neurodevelopmental outcome-case report

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Neonatal hypoglycaemia is a common complication among preterm, SGA, diabetic mothers neonates, and hypoxic-ischaemic encephalopathy, contributing to perinatal brain damage.

Case report: we present long term neurodevelopmental sequelae of the girl suffering hypoglycaemia in the early infancy. She is first born child to healthy, unrelated parents. Perinatal history uneventful. Early psychomotor development typical. At age of 3 months suffered an episode of sleepiness, floppiness, with frozen gaze, not provoked by infection or fever. Glycaemia was not checked.

At 5 months the same condition repeated, hypoglycaemia was diagnosed, accompanied by severe encephalopathy. EEG was slow, with spike-wave complexes left occipital. Genetic investigation revealed heterozygous gene for the p. R1215W mutation. Focal insulinoma of pancreas was diagnosed by F-DOPA PET-CT which was surgically treated. Afterwards, permanent normoglycemia was obtained. She underwent multidisciplinary therapeutic procedures and neuropediatric, ophthalmologic, psychologic follow up. MRI at 1 month after acute phase showed mild enlargement of the left lateral ventricle which was more expressed peritrigonaly accompanied with thinned corpus callosum at the age of 2 y (3T).

At the age of 13 months she suffered febrile seizures, at 14 months afebrile epileptic status, continuing by valproate in optimizing dosage. There are no recurrent seizures, but EEG revealed abnormal discharges. At final assessment aged 5,5 she has cerebral palsy, epilepsy, mild intellectual and cerebral visual impairment.

Conclusion: Early infant sole hypoglycaemia could cause deleterious effects on brain and multiple neurodevelopmental sequelae. Therefore, it should be checked in all clinical situations suspected on hypoglycaemia to prevent permanent harmful effect.

Relevance for users and families:

Early recognition signs of hypoglycemia of young infant in any clinical conditon such as fever, fasting, vomiting, diarrhea, to prevent permanent harmful effect to developing brain

Predictors of asymmetrical motor development in neonatal intensive care unit graduates at 3-5 months corrected age using the Hammersmith Infant Motor Evaluation

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Introduction: Asymmetrical motor development in high-risk infants has been associated with plagiocephaly, motor delays, and cerebral palsy. Although asymmetrical motor development is assessed during the HINE, the antecedents of asymmetries in young infants have not been extensively studied.

The purpose of this study was to identify associations between neonatal risk factors and asymmetric motor development using the HINE.

Patients and Methods: High-risk infants admitted to a US neonatal intensive care unit (NICU) in 2020-2021 for medical and surgical conditions were evaluated using the HINE at 3-5 months corrected age.

Results: Complete HINE Results were available for 428 infants [median postmenstrual age: 53 weeks (IQR 53-54)]; 172 (40.2%) infants were female; 276 (64.%) preterm (<37 wks); 60 (14%) with birth weights <1000g; 159 (37.1%) with brain injury/anomalies; 128 with major congenital anomalies (29.9%), and 124 (29%) had technology dependence at discharge (tube feedings, oxygen, tracheostomy).

The median HINE score was 66 (IQR: 62-69); 52 (12.1%) infants had HINE scores <57. The median number of asymmetries was 1 (0-2); 271 (63.3%) infants had >0 asymmetries and 162 (36.3%) had >1. Findings of >1 asymmetry was associated with younger postmenstrual age [53.1(+.2) vs 53.8(+.1), p=.002], brain injury/anomalies (OR 1.6, 95% CI:1.08-2.38), and technology support at discharge (OR 1.81,95% CI 1.18-2.76), but not sex, prematurity, birth weight <1000 grams or r congenital anomalies

Conclusion: Asymmetric motor development was common in high risk infants, but younger postmenstrual age, brain injuries or anomalies, and technology support at discharge were associated with increased odds of >1 asymmetry.

Relevance for users and families:

High rates of asymmetries, regardless of neonatal diagnoses, suggest that optimizing NICU environments and promoting symmetrical posture during the NICU stay should be a focus of inpatient physical therapy and discharge teaching. Motor development should be monitored closely after discharge not only as a part of screening for neurologic impairments but also to promote symmetrical development.

Multidisciplinary neuro-orthopedic clinics: Bringing together the community and tertiary specialist services

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Introduction: Children with underlying neurological and muscular difficulties make up a significant proportion of the complex orthopaedic work load. Our service had some joint working between community based therapy teams, neurodisability and orthopaedic services. However this was not universal and clear structures were not in place. A quality improvement initiative was undertaken to provide a clear pathway to optimise patient care and experience.

Material and Methods: Local data was examined to assess scope. A database was developed to capture all children in the area (South county Dublin, Kildare and Wicklow) either known or referred to orthopaedics. A focus group of orthopaedic surgeons, neurodisability consultants, physiotherapists and clinical nurse specialists was formed to design the format of a joint clinic. A focus group of community physiotherapists and occupational therapists was formed to identify challenges and solutions to pathways to the clinic from therapy services.

Results: Communication and access were identified as major issues. The joint neuro-orthopedic clinic footprint was expanded to three clinics a month to improve access. A proforma was designed to include all clinical information and outcomes. The clinics are attended by a paediatric orthopaedic surgeon, a neurodisability consultant, the community physiotherapy lead for the area, the child's primary physiotherapist, the child and family.

Conclusions: The enhanced service has improved assess and communication for service users. Waiting times are reduced and there is improved mutual support between community therapy teams and orthopaedics. Focus groups remain in place, as there is a recognised need for continued service review and improvement.

Relevance for users and families:

Relevance for users and families: This has improved patient experience and clarity around what are often complex discussions.

Hip range of motion in children with an intoed gait pattern

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Background: The intoed gait pattern (IGP) is described as a rotational variation of the lower extremities. We wanted to find out if children with IGP have increased internal hip rotation (IHP), decreased external hip rotation (EHR) and increased femoral anteversion (FAV).

Methods: Retrospectively we analyzed data of children with IGP who were referred to rehabilitation program from June 2019 to October 2022 (age, diagnosis, hip range of motion (ROM)). Descriptive statistics were calculated. Based on the norms for different age groups, we calculated the deviations (value divided by the norm) for IHR and EHR. The values for FAV were compared graphically with available data from the literature. We defined the better side (BS) and worse sides (WS) according to the deviation from the norms.

Results: We included data of 44 children (15 boys; mean age 6.8 years). The average IHR of the WS/BS was 73.2° (SD=9.5)/68.1° (SD=10.3). The average EHR of the WS/BS was 26,3° (SD=8.6)/31.6° (SD=9.0). The average FAV of the WS/BS was 43.9° (SD=8.5)/39.3° (SD=9.9). The average IHR was higher than normative data for the corresponding age group for BS/WS by a factor of 1.37 (SD=0.21)/1.48 (SD=0.19); EHR for BS/WS by a factor 0.63 (SD=0.20)/0.53 (SD=0.20). Comparing with available data the majority of included children had higer FAV.

Conclusion: Children with IGP had increased mean IHR, decreased mean EHR and increased FAV. Our sample Results of FAV are dispersed, probably due to different anatomical reasons for IGP which was the main referal diagnosis.

Relevance for users and families:

Children with intoed gait pattern had increased mean internal hip rotation, decreased mean external hip rotation and increased femoral anteversion. It stays unclear which, if any therapy approach needs to be applied.

Utility of developmental assessment for early intervention in young children with ASD

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Introduction: Early diagnosis of young children with Autism Spectrum Disorders (ASD) needs to be followed by effective interventions to support their overall development. However, access to and availability of intervention services varies across regions, making early intervention challenging for many. Developmental assessments may be administered to assist diagnostic workouts or to monitor child's development and progress. At such, it is a promising tool to empower parents.

Patients and Methods: Children were recruited from the Child Development Centre of a teaching hospital in Malaysia after diagnosis as part of a larger trial to screen for ASD in young children. The Griffith Scales of Child Development (Griffiths-III) which provides a profile of strengths and weaknesses for the child across 5 areas of development was administered to 20 children with ASD below the age of 36 months. The young child is accompanied by parents during the assessment.

Results: Almost half of the children (45%) were an only child and both parents work in 75% of the families. Significant delays were found in the areas of language and communication as well as personal-social-emotional corresponding to the core features of ASD. All the parents reported that they have gained new information about their child after the assessment and have a better idea of what to do at home.

Conclusion: Developmental assessment provides an overall profile of both strengths and weaknesses in the child. This can guide parents in setting goals for intervention at home without depending on services.

Relevance for users and families:

Parents (especially new ones) can understand their ASD child's functioning from developmental assessment and use it to develop a suitable home program together with their clinicians.

When parents participate in the assessment session, they have the opportunity to observe the interaction between assessor and child as well as behaviour management strategies in action. This direct learning through modelling by the professional is important and demonstrates efficacy to empower parents.

Impact of blended education system on outcome based Learning and sector skills development

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Blended education is the smart combination of online, offline and recorded mode of content development and teaching Methods to facilitate the choice-based education and certification programme. The modern education system is focusing on outcome-based teaching and learning that creates link between the education system and industry. The motive of initiating the research work was to address the Blended Education System and the scope of competent education system with the sector wise career planning and development. The research initiative helps to design of course and degree with the facility of choosing your subjects, lectures and teachers either in online or offline mode of education. The system may also assist for preparing the learning pattern like classroom-based learning, internship-based learning or learning through project works. The technology and smart networking system build the efficient Institutional Support System for implementing the digital mode of assessment and evaluation process. The researchers identified the dependent and independent variables with the help of expert opinion. The questionnaire was designed with all relevant questions based on the variables and refined through pilot study. Statistical tools like frequency distribution, t-test and ANOVA test were implemented for data analysis and interpretation. The principal outcomes of the present study describe the impact of blended education system on outcome-based learning that will transform human being into something useful for the organization and society.

Relevance for users and families:

Not received.

Clustering of premature and unnatural deaths in families of children with special needs

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Introduction: This study was done on children consulting developmental pediatrician for different developmental concerns and behavioural complains. Children were chosen from clinical population, who were diagnosed with ASD by using Autism Diagnostic Observation Schedule-2 and Autism Diagnostic Interview–Revised, ADHD by using Conners, GDD by using Bayleys-3/Griffiths/WISC.

Patients and methods: The total sample consisted of n=50 children with special needs with the mean age being 5 years 2 months. A detailed family history from both paternal and maternal side, covering up to three generation, was collected from parents/informants of children using a semi-structured interview, following which data analysis was done. Results: Findings indicate that 32% families have history of suicidal deaths, 40% have mortality associated with accidents (road accidents, fire, bomb blast etc) and 4% deaths due to undetected reasons. The percentage of premature deaths due to variour similar and dissimilar causes was found to be 58, with neonatal deaths and miscarriages found in 14% and 18% of the families respectively.

Conclusion: It may be concluded that there is a noteworthy aggregate of premature and unnatural deaths seen in history of families of children with special needs. This draws our attention toward the potential role of such familial occurances in perpetuating an environment of psychological distress that directly or indirectly affects the prognosis of such children. Such high occurances of premature death due to medical causes are also indicative of inheretance of abnormal genes that are phisiologically relevent and thus should be accounted in the treatment plan of such children.

Relevance for users and families:

Families with recurrent history of premature and unnatural deaths and having children with special needa should be provided counselling and consistent support to deal with the resultant trauma and distress and create a protective environmnet for their children's development. They ought to be screened for genetic defects as there could be plausibly genetic factors that are passed in the family, predisposing the offspring to neurodevelopmental disorders.

The effectiveness of Special education intervention in children with Attention Deficit Hyperactivity Disorder

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Introduction: Children with ADHD has a difficulty in sustaining attention, gets distracted while putting mental effort in some challenging tasks. The aim of the current study focuses on the effectiveness of special education through Kolkata Development Model.

Patients and Methods: Vanderbilt ADHD Diagnostic Teacher Rating Scale, was administered among a sample of 20 school going students in the age range of 6-14 years, from middle socio-economic background. In the current study, the experimental group (10 students) was provided multidisciplinary treatment along with special education services and the control group (10 students) was provided only MDT intervention. Both the groups were provided with 6 months of special education services. Reassessment of Vanderbilt ADHD Teacher Rating Scale was conducted.

Results: The results revealed that, students who received special education services had a better performance in higher executive functions, customised teaching result in better academic performance, there was an improvement in behavioural areas, as well as incorporation of assistive devices, helped them to learn more effectively and meet the short term objectives. Special educators used instructional strategies where they encourage students to think by themselves, use their own words and elaborate on their ideas, encouraging student participation.

Conclusion: Special education treatment is important in adjunct to multidisciplinary treatment among special needs children.

Relevance for users and families:

Remedial Education has been considered as an adjunct intervention with other therapies, in India and is an established intervention.

Early childhood intervention familiy's role

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Objective: The importance of family role in the multidisciplinary team of child's rehabilitation early intervention.

Learning objectives: Scientific and legal background of early intervention, definitions, good practices and applications, family's roles.

Audience: Scientists involved in rehabilitation processes, families, parents, caregivers.

Summary: Central nervous system development is the result of both Intrinsic/Genetic and Extrinsic/Environmental Factors' impact. Development is a highly interactive and sensitive process that is not exclusively determined by genes. The architecture of the brain for the most part is formed in the period from conception to the first three years after birth. Early brain damage can lead to lifelong problems. Neuroplasticity of the developing brain in the early years of life is characterized mainly by: Easy synapse formation, Easy change of existing synapses, and Non-consolidation of neural circuits. Thus, Neuroplasticity is the basis of Early Childhood Intervention concept. Apart from the scientific documentation of Early Childhood Intervention, there is also a strong legal cornerstone. Children's rights are essential components of the conceptual framework. The term early childhood intervention is used for "services provided to children from birth to 3 years of age who are at risk or have developmental delays or isabilities", and relies on family centered routines and natural learning environments, is a multidisciplinary team work and coordinates services and resources. Early Intervention in ELEPAP, includes all the measures, services, treatments and benefits available in order to prevent the occurrence of neurological disorders from pre and perinatal events.

Outline: Conceptual framework, ELEPAP's prctices, conclussions, referances.

Relevance for users and families:

Importance of family involvement in early childhood intervention, therapeutic and educational strategies, goal setting, assessment, multidisciplinary work, follow up, outcomes.

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