

## 2024 SA-ACAPAP Congress

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**SEARCH:** Use ctrl-alt-F

### The effect of integration of the fear paralysis reflex on the occupational performance of children with handwriting problems

Mrs Jenine Bence 1, 2, 3, 4, 5, Mrs Arifa Sheik Ismail 1, 4, Professor Nicola Ann Plastow 1, 4

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**BIOGRAPHY:** Jenine Bence is an occupational therapist with 37 years' experience of working with children in private practice with neuro-developmental delay, dyspraxia, sensory modulation, processing and integration-, social-emotional-, and learning and behavioural difficulties. Diagnoses included Developmental Coordination Disorder, Attention Deficit Disorder, Attention Deficit Hyperactivity Disorder, Autism Spectrum Disorder, Dyslexia, Tourette's Syndrome and Cerebral Palsy.

Jenine noticed that when using Ayres Sensory Integration®, these children also improved in their emotional functioning. She thought there should be an underlying central nervous system reason why sensory processing disorders and behavioural problems are prevalent in about 15% of children, especially boys. Her two adult sons, a computer scientist and an electronic/electrical engineer, also needed Ayres Sensory Integration® therapy during early childhood. The origin of developmental difficulties, and why treatment of sensory integration difficulties improves the emotional development of the child, became a quest.

Use of Interactive Metronome® started a non-speaking 5 year old client with choreoathetoid cerebral palsy to babble and talk in 2013. Subsequent Tomatis® Method auditory integration and DIR Floortime® Ayres Sensory Integration® sessions with her mom helped her to start attending a small group school setting in 2015. Intermittent occupational therapy continued into Masgutova Neuro-sensory-motor Reflex Integration®) (MNRI®) sessions during 2016-2017. This included a few Post Traumatic Stress Disorder Recovery sessions through MNRI® reflex integration. These approaches including SandtrayPlay therapy, were implemented with various other children with their parent/s. Jenine also attended Attachment and Trauma training courses. https://attach.org/

As part of the quest, Jenine started using reflex integration from Rhythmic Movement Training International (RMTi) with children with an unintegrated fear paralysis reflex and primary reflexes, since 2018. When she used RMTi Rhythmic Movements during occupational therapy, Jenine noted quick positive changes in the children's drawings or handwriting and willingness to participate in an activity or task, which previously often was straightforwardly refused.

**Introduction:** Unintegrated primary reflexes and subsequent delayed cortical maturation lead to learning/behavioural problems in children. Rhythmic Movements integrate the Fear Paralysis Reflex (FPR), the first lifelong, protection, reflex. No effectiveness evidence of FPR integration was found. The aim was to determine the effect of FPR integration on the occupational performance of children using Rhythmic Movement Training International (RMTi) Rhythmic Movements.

**Methods:** Participants included 14 grade 2-3 children (Male=13; Female=1), aged 8-9 years with handwriting problems, attending four public schools in Cape Town, South Africa. Change in occupational performance from the child's perspective was evaluated using the Canadian Occupational Performance Measure after 6 hours of FPR integration. A time series cross over design with random allocation and delayed control intervention was used. Assessment was at baseline test 1 and 2, midintervention test 3, two weeks post intervention test 4 and at 12-15 weeks post intervention test 5. Intervention included eight, weekly individual RMTi FPR integration sessions with an occupational therapist, and a carer led RMTi Home Support programme 3-4x p/w.

**Results: All** 14 children presented with an unintegrated FPR, lack of sensory integration, poor quality of handwriting, and low levels of performance and satisfaction in daily occupations. Within participant repeated measures analysis showed that the children improved in their performance (p=0.002) of a range of occupations that they identified as important, and increased in satisfaction (p=0.003) with their performance. Similarly the caregivers' ratings of performance (p=0.011) and satisfaction (p=0.011) for occupational performance problems in their children, improved.

**Conclusion:** FPR integration (p=0.003), sensory processing (p=0.025), handwriting speed (p=0.001) and occupational performance (p=0.002) improved. FPR integration could shorten the intervention period needed to improve neuro-behaviour. Caregiver involvement in RMTi Home Support under guidance of therapists could become a means to help the majority of the South African community who cannot afford individual therapy.

### How do we de-medicalize mental health for child protection officers and the children in their care?

#### Dr Deirdre (Dee) Blackie<sup>1</sup>

<sup>1</sup>Courage Child Protection & Empowerment, Johannesburg, South Africa

**BIOGRAPHY:** Dr Dee Blackie is a child protection researcher and community worker in Johannesburg South Africa. Following a 15-year career in business consulting and change management, she started working with communities concerned with child protection, child abandonment and adoption in 2010. She facilitated the creation of a National Adoption Coalition for South Africa in 2011, and since then her primary focus has been on creating awareness and engaging with communities around child protection challenges. Her master's research (Wits) explored the lived experience of child abandonment and adoption in South Africa, and her PhD research (Wits) has taken her into the field of disability, with a specific focus on atypical and neurodiverse children. Dr Blackie launched Courage in 2015, a trauma informed community engagement programme aimed at assisting child protection officers and communities to address challenges spanning child abuse, neglect, exploitation and harmful cultural practices. Over the past nine years she has used this programme and toolkit to empower meaningful change in the care and protection of children in many communities across Africa and around the world.

Medicalization describes the process through which nonmedical challenges become defined and treated as medical problems, usually in terms of disorders or illness. Through medicalization, we see how society can be divided into those who are viewed as healthy and those who are deemed sick or deviate from what is considered 'normal'. The process has become well documented across many medical categories including childbirth, addiction and more recently the rapid expansion of the mental health category. Many argue that much of this category has medicalized what used to be considered nonmedical challenges, such as feeling sad, anxious, or struggling with one's identity, self-esteem, or approach to learning. The challenge of medicalization is that it can take much of the responsibility of managing the new medical category and placing it solely in the hands of the medical fraternity and the prioritization of formal medical diagnoses before intervention can take place. In doing this, non-medical, often community-based child protection officers including social workers, teachers, sports coaches, parents, and NGO care workers, feel disempowered to engage meaningfully in the support of the mental health of children in their care. Using insights gained from eight years of community-based workshops and participant observation into child protection challenges with predominantly non-medical child protection officers, Courage has developed a Mental Health and Harmony programme. The programme, still in its pilot phase, has been positively embraced as an overarching tool to create a shared, 'bottom up', community-based language and understanding of mental health by non-medical child protection officers in the support and care of children and their mental health journey.

### Patterns of sensory integration dysfunction in South African children as identified by the Evaluation in Ayres Sensory Integration®

#### Mrs Marica Botha<sup>1</sup>

<sup>1</sup>University of the Witwatersrand, Johannesburg, South Africa

**BIOGRAPHY:** Marica Botha has been a full-time paediatric occupational therapy lecturer at the University of the Witwatersrand since June 2018. She obtained her undergraduate degree at the University of Stellenbosch in 1997 and after qualifying worked in paediatric private practice, with another therapist, and later her own practice from 1998 to June 2018. She started working as a part-time clinical supervisor at WITS in 2009 and decided to do an M.Sc. Occupational therapy. She is currently also a Ph.D. candidate at WITS. She has a special interest in Ayers Sensory Integration® *and has served on the board of the South African Institute for Sensory Integration since 2009.* 

Introduction: Presentation to present the planned study and some findings on study phase one on the sensory integrative patterns of dysfunction as determined by the Evaluation in Ayres Sensory Integration (EASI) in a population of South African children. Occupational performance can be influenced by sensory integration (SI) functions. SI functions comprise sensory, motor, and praxis functions. Accurate evaluation of SI functions is essential for evidence-based intervention. With the development of the new ASI test, the EASI has started to provide an affordable, practical, and accessible test that has appropriate norms for the international population in which it will be used. To effectively plan treatment, test results must be interpreted. On the current Sensory Integration and Praxis test, cluster patterns of sensory integration dysfunctions are used for assessment interpretation and treatment planning. Thus, information on the patterns of sensory integration dysfunctions is needed for the newly developed EASI test.

**Methods:** The study will be divided into three parts: Phase one is a scoping review of the literature to determine and describe all currently published research on the patterns of sensory integrative dysfunction in children based on the Ayres Sensory Integration® Framework. In phase two, the patterns of dysfunction will be determined through a factor analysis. These data will then be used to develop the typology for test interpretation. During phase three of the study, the patterns of sensory integrative dysfunction in South African children as identified by the EASI, will be compared with the patterns of dysfunction as identified previously in the literature to determine any similarities or differences.

### The benefits of sharing the House-Tree-Fire-Water-Person drawings of anxious children with their parents

Mrs Judith Bredekamp<sup>1</sup>, Prof Linda Theron1

University of Pretoria, Cape Town, South Africa

**BIOGRAPHY:** Judith Bredekamp - I am currently pursuing a Ph.D. at the University of Pretoria's Faculty of Education. My academic journey began with an undergraduate degree and Higher Diploma in Education from the University of Cape Town and a Master's degree in Educational Psychology from the University of Stellenbosch. Between my undergraduate and master's degrees, I taught at High school and then Primary School level for a period of 13 years. In addition, I bring my experience as an internationally certified sandplay therapist, focused on assisting children facing diverse mental health challenges. I have had the privilege to present at mental health gatherings, notably the IAAP Congress in Vienna and most recently the 2023 PSYSSA Congress. These experiences of sharing research have contributed to my own professional development on my learning and teaching journey. To restore my energy and balance the challenges of work, I paint, walk with family and friends and enjoy the experience of nature. I am excited to exchange ideas with colleagues who are also committed to nurturing well-being and resilience in the field of paediatric mental health.

**Introduction:** The objective of my paper is to present the advantages of integrating the House-Tree-Fire-Water-Person (HTFWP) drawing method as an adjunct within the framework of sandplay therapy for anxious children aged 10-12. Highlighting the pivotal role of a robust parent-psychologist alliance in the course of a child's therapeutic journey, contemporary empirical research underscores its critical significance. Building upon this empirical foundation, my study addresses gaps within the prevailing literature concerning the parent-psychologist alliance, sandplay therapy, and child-client drawings. Additionally, my investigation explores the advantages linked to sharing HTFWP drawings with parents during feedback sessions, with the child's informed consent, aiming to contribute to the advancement of the field of child psychotherapy.

**Methods:** Employing an exploratory, instrumental, multiple case study design rooted in the Social Ecological Theory of Resilience, my research examined 7 purposefully selected cases involving primary (parents) and secondary informants (child-clients). Utilizing reflexive thematic analysis to identify patterns in the data, we uncovered the value of sharing HTFWP drawings.

**Results:** Related themes indicated that a collaborative synergy between parents and psychologists, facilitated by the sharing of HTFWP drawings, engenders positive outcomes on different fronts. These include enhanced care for the child, augmented parental support, and heightened therapist efficacy. The practice of sharing HTFWP drawings with parents, with the child's consent, emerged as a valuable method.

**Conclusion:** My study contributes to the field of child psychotherapy by fostering the parent-psychologist alliance and enhancing parental insight into their child's anxiety. This, in turn, fosters more effective parenting practices to support the child's therapeutic progress and resilience, while concurrently supporting psychologists in their therapeutic role. By adopting my approach, psychologists can refine their observational abilities and access a visual representation of therapeutic progress. Ultimately, this research enriches the therapeutic process, yielding positive outcomes for anxious children, their caregivers, and the psychologist alike.

### The Open Source Screening and Diagnostic Tool for autism (OSSDx) – feasibility findings from South Africa

<u>Dr Erin Campbell</u><sup>1</sup>, Dr Rebecca Searle<sup>2</sup>, Ms Eva Mwangome<sup>4</sup>, Professor Amina Abubakar<sup>3</sup>, Professor Melissa Gladstone<sup>2</sup>, Professor Petrus de Vries<sup>1</sup>

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Biography: Erin is a medical doctor and Junior Research Fellow at the Centre for Autism Research in Africa.

**Introduction:** Most autistic children live in low/middle-income countries with little or no access to screening and diagnostic tools. Assessment tools are typically developed in high-income contexts often subject to expensive training and purchase of copyrighted materials. Thus, existing tools may not be well-suited to reduce the identification gap for autism around the globe. This study aims to develop user-friendly, culturally appropriate screening and diagnostic tools for autism that are accessible, acceptable, and applicable to the global community, and that will allow non-experts in autism to make accurate diagnoses in community settings.

**Methods:** The Open Source Screening and Diagnostic Tool project (OSSDx) is a multi-country project (South Africa, Kenya, UK) using a multistage mixed methods approach. Stages 1-5 used construct mapping and Delphi methodology to identify relevant items for inclusion in a draft prototype. Stage 6A included performing cognitive interviews with ten caregivers. Stage 6B included administration of the prototype screening and diagnostic tool to purposively sampled families with an autistic child or a child with another neurodevelopmental disorder. Qualitative and quantitative data on acceptability of content, format, duration and procedure, as well as cultural appropriateness were collected.

**Results:** Twenty South African families were included with 10 completing the screening and 10 the diagnostic tool. Here we will present the mixed-methods feasibility findings from participants of Stage 6B.

**Conclusion:** Findings from stage 6 informed revisions to the OSSDx tool to use in Stage 7. This will include piloting of the refined tool to investigate the acceptability of assessments and materials, and an early-stage evaluation of psychometric properties. We hope that final OSSDx tool will be an acceptable, affordable and culturally appropriate instrument that can be used in next step larger-scale validation studies around the globe.

### Unravelling a complex case of a non-walking 12-year-old - when trauma complicates clinical presentation

Mrs Gina Rencken<sup>1, 2</sup>, Mrs Ray Anne Cook<sup>1</sup>

<sup>1</sup>SAISI, Pretoria, South Africa, <sup>2</sup>University of KwaZulu-Natal, Westville, South Africa

**BIOGRAPHY:** Ray Anne Cook has been an active occupational therapist in special schools and private practice for over 35 years. She was the director of Sensorykidzone, specializing with children and adults with sensory integration difficulties, Autism and ADHD. At present she is doing more mentoring and working with adults. Masters in sensory processing and ADHD was driven by person experience of my son and myself living with ADHD. My passion is the misunderstood child, empowering their parents in the upbringing of their child and developing the art of playfulness in all of us. She has been involved in the South African Institute for Sensory Integration for 30 yrs, as a board member and lecturer. She is the head for training Ayers Sensory Integration in South-Africa. She is on the EXCO of the South African Association for Child and Adolescent Psychiatry. She has recently moved to Plettenberg Bay to retire part time

A 12-year-old child visiting South Africa from Uganda presented to medical care with reports of not being able to walk unassisted. He was examined by an orthopaedic surgeon as well as a neurodevelopmental paediatrician, both of whom found no medical or physical pathology to explain this. A psychogenic cause of his physical challenges was suspected. An urgent referral to psychiatry was requested, but not possible as the family had limited time before returning home. He was referred to Occupational Therapy by a psychologist and commenced intensive therapy for the duration of the time he had remaining in South Africa.

An in-depth, but rapid clinical reasoning process was followed, considering his developmental and chronological age, the presenting problems, factors influencing this and how these could be restored. This indepth case study will explore this process, delving into the decision-making and influencing factors in each step and highlighting the role of specifically tailored occupational therapy using evidence-based approaches, and the contribution to the holistic care of this complex case in a multi-disciplinary team.

### Reasons for Referral and Assessment Results at Ububele Pre and Post COVID-19

Ms Sherylene Ganesh<sup>1</sup>, Dr Nicola Dawson<sup>1</sup>

<sup>1</sup>Ububele Education and Psychotherapy Trust, Johannesburg, South Africa

**BIOGRAPHY:** Dr Nicki Dawson is a registered Counselling Psychologist and the Research and Development Lead for the Ububele Educational and Psychotherapy Trust. She completed both her Masters in Community-Based Counselling Psychology and her Doctorate in Psychology at the University of the Witwatersrand. Her doctoral research investigated the intersection of sensitive responsiveness, culture and context. Nicki's professional career has had a special focus on infant mental health. Prior to her appointment as the Research and Development lead, Nicki spent 7 years working as the Ububele Parent-Infant Manager, overseeing the implementation of various infant mental health interventions including the Ububele Home Visiting, Baby Mat, and NBO services. Nicki is appointed as a lecturer extraordinary at the University of Stellenbosch, on the Masters in Infant Mental Health course. She is also the secretary for the South African Association for Infant Mental Health.

**Background:** The COVID-19 pandemic placed huge additional strain on already stressed South African households. In poor and densely populated areas such as Alexandra, thousands of South Africa's most vulnerable families were confined in large numbers to small informal houses and families faced the stress of food insecurity and growing unemployment. Education was severely disrupted by regular school closures, and socio-economically disadvantaged children were particularly impacted, due to pre-existing overcrowding in schools and low access to remote learning. International literature has documented rises in mental health and school achievement problems after the pandemic. Local literature is limited.

**Methods:** This study presents a quantitative analysis of the reasons for referral, psychoeducational assessment results and preschool readiness results of Ububele's beneficiaries pre and post the COVID pandemic.

**Results:** An analysis of referrals to Ububele pre and post COVID revealed an increase in overall numbers of referrals, and a statistically significant increase in referrals relating to trauma experiences, depression, anxiety, and suicidality. Pre and post COVID differences were also observed in the performance on psychoeducational assessment and school readiness assessments.

**Implications:** Therapeutic services for Alexandra residents should place special focus on working with trauma, depression, anxiety and suicidality. Urgent support for school learners in Alexandra is needed.

### The NBO as a Preventative Infant Mental Health tool for Southern Africa

Ms Sherylene Ganesh<sup>1</sup>, Dr Nicola Dawson<sup>1</sup>

<sup>1</sup>Ububele Education and Psychotherapy Trust, Johannesburg, South Africa

**BIOGRAPHY:** Dr Nicki Dawson is a registered Counselling Psychologist and the Research and Development Lead for the Ububele Educational and Psychotherapy Trust. She completed both her Masters in Community-Based Counselling Psychology and her Doctorate in Psychology at the University of the Witwatersrand. Her doctoral research investigated the intersection of sensitive responsiveness, culture and context. Nicki's professional career has had a special focus on infant mental health. Prior to her appointment as the Research and Development lead, Nicki spent 7 years working as the Ububele Parent-Infant Manager, overseeing the implementation of various infant mental health interventions including the Ububele Home Visiting, Baby Mat, and NBO services. Nicki is appointed as a lecturer extraordinary at the University of Stellenbosch, on the Masters in Infant Mental Health course. She is also the secretary for the South African Association for Infant Mental Health.

**Background:** This presentation will showcase the utility and benefits of the Newborn Behavioural Observation (NBO) System as a culturally sensitive, low-resource infant mental health intervention model for Low and Middle Income Countries (LMICs) such as South Africa. This Harvard-developed tool has been demonstrated to positively impact on various contributors to infant mental health, including maternal mental health and sensitivity to the infant, confidence and knowledge of practitioners, and infant development. The NBO also provides a potential avenue to protect the developing neonatal brain from stress, which can impact on later socio-emotional and cognitive functioning, preventing child and adolescent mental health conditions.

**Methods:** This presentation will provide an overview of the NBO tool before going on to describe the incorporation of the NBO into service provision in collaboration with a South African Johannesburg municipality's health department and district hospital. Survey results from over 300 parents living in Johannesburg, South Africa who received an NBO will also be shared.

**Results:** The Newborn Behavioural Observation System is a low-resource infant mental health tool, which can aid in the prevention of child and adolescent mental health conditions. Families using public health care services, living in Johannesburg, South Africa report finding the NBO useful for learning about their infant and improving attachment-promoting infant care.

**Conclusion:** The Newborn Behavioural Observation System is an appropriate, low-cost infant mental health tool with great potential benefit for implementation in South Africa and surrounds, in aid of the prevention of late child and adolescent mental health difficulties.

### Structural connectivity of brain networks in young children exposed to maternal depression: Findings from a South African birth cohort

<u>Dr Nynke Groenewold</u><sup>1,2</sup>, Dr Richard A.I. Bethlehem<sup>3</sup>, Ms Alyssa R. Amod<sup>1,2</sup>, Dr Emmanuel C. Nwosu<sup>1,2</sup>, Dr Farai Mberi<sup>1,2</sup>, Dr Catherine J. Wedderburn<sup>2,4,5</sup>, Dr Jennifer A. Pellowski<sup>6</sup>, Dr Annerine Roos<sup>1,2,7</sup>, Prof Heather J. Zar<sup>5,8</sup>, Prof Kirsten A. Donald<sup>2,5</sup>, Prof Dan J. Stein<sup>1,2,7</sup>, Dr Jonathan C. Ipser<sup>1,2</sup>

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**BIOGRAPHY:** Dr Groenewold is a Senior Lecturer in the Department of Psychiatry and Mental Health and at the Neuroscience Institute of the University of Cape Town, South Africa. She has a background in clinical psychology and neuroscience. Her main research expertise concerns neuroimaging of depressive and anxiety disorders throughout the lifespan. In 2021-2022 she was awarded a Carnegie Developing Emerging Academic Leaders Fellowship to study changes in brain development following adverse antenatal exposures in South African children, with a special emphasis on maternal depression exposure. She currently leads a study on emotional disorders in South African adolescents as well as collaborative international research projects on anxiety disorders as part of ENIGMA-Anxiety. In addition, she is PI of an NIMH R01 grant that investigates early brain development in children born to depressed mothers in high-income and low-income settings.

**Introduction:** Perinatal maternal depression is an important global mental health concern that disproportionately impacts children in low- and middle-income countries, such as South Africa. Maternal depression exposure has been linked to differences in brain structure of frontal and limbic brain regions, but mostly in high-income settings. Therefore, the current study investigated structural connectivity between frontolimbic brain regions after maternal depression exposure in two-to-three year old children from a South African birth cohort.

**Methods:** Antenatal and postpartum maternal depression assessments were conducted with the Beck Depression Inventory II and Edinburgh Postnatal Depression Scale. T1-weighted brain MRI scans from 142 children (age m=2.87 years; 57.75% male) were available for analysis. Cortical thickness estimates were extracted for brain regions from the Gordon atlas using FreeSurfer software. Morphometric integration scores were calculated across brain networks. These metrics were compared in children that were exposed to maternal depression (n=22 antenatal, n=20 postpartum, n=16=both) relative to unexposed children (n=64).

**Results:** Children that were exposed to maternal depression at both the antenatal and postpartum timepoints showed weaker morphometric integration in the frontoparietal brain network (t=2.559, p=0.013) compared to unexposed children. However, no group differences were found following only antenatal or postnatal exposure. Further, no group differences were recorded in other networks that include frontal or limbic cortical regions.

**Conclusions:** These results support previous findings from this cohort, specifically the observation of smaller bilateral amygdala volumes in children exposed to persistent maternal depression. Together, these findings suggest that maternal depression that persists across pregnancy and the postpartum period impacts the early development of frontolimbic brain networks, more so than antenatal or postpartum exposure alone. Accordingly, prevention of persistent depression in new mothers may possibly benefit early neurodevelopment in their children.

## Adolescent Social Media Use: Privacy & Mental Health (ASMUM) What is the association between having a publicly available social media account and anxiety and depression in adolescents?

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**BIOGRAPHY:** "Dr Wakithi Mabaso graduated from the University of Cape Town (2019) with an MBChB (cum laude) before completing his medical internship in Pietermaritzburg, KwaZulu Natal and community service in Uitenhage, in the Eastern Cape. As an aspiring clinician-scientist passionate about mental health with an interest in psychiatry, he will read for an MSc in Clinical Neuroscience, having completed an MSc in Epidemiology at the University of Oxford on the Rhodes Scholarship.

**Introduction:** Associations between social media use and adolescent mental health have been described. New characterisations of social media use can advance our understanding of this complex exposure, with a focus on social media privacy, content and platforms accessed by adolescents.

**Methods:** Eighty secondary schools/further education colleges in England were sampled using a cross-sectional online survey. Social media privacy was categorised into adolescents with a public account vs. a private account/no public account. Risk of clinical anxiety and depression was determined using the revised children's anxiety and depression scale. Adolescents reported content and platforms accessed in the last 24 hours. Associations between having a public account and anxiety and depression were assessed using logistic regression controlling for age, sex, bullying, online parental guidance, proportion of close friendships engaged online, poverty and maltreatment. Age sex and online parental guidance were assessed for effect modification.

**Results:** The study analysed 16,655 adolescents (11 - 18 years). Forty percent had publicly available social media accounts, 32.6% screened positive for anxiety and depression and adolescents with public accounts had higher odds of anxiety and depression (OR: 1.41, 95% CI: 1.32-1.50) compared to adolescents with private accounts in an unadjusted model and in a fully adjusted model (OR: 1.39, 95% CI: 1.29-1.49). Adolescents reporting active parental guidance had lower odds of anxiety and depression (OR: 0.85, 95% CI: 0.75-0.93) compared to those reporting no parental guidance. Online parental guidance significantly modified the association between social media privacy and anxiety and depression (p = 0.004,  $\chi$ 2 = 11.05) Entertainment was the most accessed content type (75.8%) and YouTube the most accessed social media platform (83.5%).

**Conclusion:** Findings support social media privacy as a mental health risk factor in adolescents. The role of online parental guidance in supporting the mental health of adolescents is highlighted for further investigation.

### Prevalence of depressive and anxiety symptoms among caregivers of children and adolescents with mental illness in two treatment centers in Botswana

<u>**Dr Tseleng Maphane**</u><sup>1</sup>, Dr Phillip Opondo<sup>1</sup>

<sup>1</sup>University of Botswana, Gaborone, Botswana

**BIOGRAPHY:** Dr Tseleng Maphane is a final year registrar in Psychiatry in the University of Botswana. She is part of the pioneering cohort of locally trained post graduate trainees in psychiatry. Inspired by the dire lack of specialized child and adolescent services, she has aspirations to specialize in child and adolescent psychiatry, and develop the field in her country.

**Introduction:** Globally, 15% of children and adolescents suffer from mental illness. Several factors affect mental health outcomes for this population. These include caregiver burden and psychological health of those providing care. The aim of this study was to determine the prevalence and correlates of depression and anxiety disorders among caregivers of mentally ill children and adolescents presenting at Sbrana Psychiatric Hospital and Princess Marina Hospital psychiatric clinic.

**Methods:** A cross sectional study was conducted in the two referral hospitals between July 2022 and February 2023. The Patient Health Questionnaire 9 (PHQ9) and the Zung Self rating Anxiety Scale (SAS) were used to measure symptoms of depression and anxiety in the caregivers respectively. Data was analysed using SPSS. Bivariate analysis was used to measure associations between dependent and independent variables, and significant associations were recruited into multivariate analysis to generate adjusted odds ratios.

**Results:** A total of 110 participants were recruited, a majority of whom were female (89.1%). Forty-two (38.2%) caregivers had depression symptoms, 42.2% reported anxiety, whereas 28.2% had both depression and anxiety. Having a child with a greater degree of functional impairment was associated with both depression (AOR 1.07, p=0.002) and anxiety (AOR 1.09, p=0.003). There was a significant association between lower monthly income and anxiety in the caregiver (AOR 3.04, p=0.043).

**Conclusion:** This study demonstrates high prevalence of depressive and anxiety symptoms among caregivers of children and adolescents with mental illness. It is therefore important to incorporate addressing the caregiver's psychological health while treating the children and adolescents.

# Putting cultural difference in its place: Barriers to access to health services for parents of children with intellectual disability in an urban African setting

#### Dr Siyabulela Mkabile<sup>1</sup>

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BIOGRAPHY: Dr Siyabulela Mkabile is a clinical psychologist and lecturer in the department of psychology at the University of Cape Town. He trained as a clinical psychologist at the University of Western Cape and subsequently graduated with his PhD at Stellenbosch University. He is the recipient of the prestigious Bongani Mayosi scholarship. He has more than 13 years of experience as a senior clinical psychologist working in intellectual disability services at the Department of Health, Cape Town. His work focuses on childhood intellectual disability, and he says, "People with intellectual disability resonate with me as a black South African growing up in the rural parts of the Eastern Cape, because they too know what it feels like to be neglected and they too struggle to access appropriate services. I feel this is the group in society that really needs professionals like myself and the specialised services we can offer." His work has been published in prestigious journals, including Comprehensive psychiatry, Journal of Applied Research in Intellectual Disability, African Journal of Disability, Transcultural Psychiatry, Journal of intellectual disabilities, Journal of Disability & Religion and International Journal of Social Psychiatry.

**Background:** Access to appropriate specialist level services for children with intellectual disability is challenging in Africa, with very few services available. Much literature on the utilisation of services by carers of children with intellectual disability in Africa emphasises the supposed incompatibility between indigenous and western beliefs, failing to identify more obvious, embodied barriers to access to care.

**Method:** As part of a study on children with intellectual disability in Cape Town, South Africa, we interviewed caregivers regarding the difficulties in accessing care, specifically the complex, expensive and time-consuming travelling routes from home to care.

**Results:** Caregivers discussed the embodied difficulties accessing care. Everyday struggles with transport, and crowded, dangerous and hostile environments were identified as barriers to care.

**Conclusion:** These challenges are often overlooked in the literature, in favour of an emphasis on cultural difference. This dualistic view of the world may obscure more obvious reasons why people find it difficult to use services, even when they are available.

## Prevalence and factors associated with depression and anxiety among young adolescents aged 10 to 14 years in school settings in the Western Cape Province.

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**BIOGRAPHY:** Mirriam Mkhize is a clinical social worker and a Sue Struengmann Initiative research fellow at the Alan J. Flisher Centre for Public Mental Health at the University of Cape Town's Department of Psychiatry and Mental Health. Her current research focuses on adolescent emotional well-being and mental health, as well as the co-adaptation and testing of a World Health Organization's Early Adolescents Skills for Emotions (EASE) group-based programme aimed at reducing depression and anxiety among adolescents aged 10 to 14 years and their caregivers. She has expertise providing psychosocial support and counselling to children, adolescents, and adults in multiple settings throughout South Africa.

**Introduction:** Between 10 and 20% of children and adolescents globally experience common mental disorders (CMDs) such as depression or anxiety. Given the dearth of mental health services in low- and middle-income countries, most mental disorders among adolescents remain undiagnosed and untreated. In South Africa, few studies have explored the prevalence of CMDs among young adolescents aged 10-14 years. This study examined the prevalence and factors associated with CMDs among school-going adolescents in the Western Cape Province of South Africa.

**Methods:** A descriptive cross-sectional study was conducted in 10 schools in the Western Cape Province from February to July 2022. Data was collected using a tablet-based survey and included sociodemographic items, the Generalized Anxiety Disorder 7-item scale (GAD-7), the Patient Health Questionnaire for Adolescents (PHQ-A) to measure depressive symptoms and other psychosocial factors associated with CMDs, such as traumatic experiences. The prevalence of CMDs were estimated based on cut-off scores for the GAD-7 and PHQ-A. Multivariable logistic regression models were used to investigate the associations between sociodemographic and psychosocial factors, and depression and anxiety.

**Results:** Of the 621 adolescents, 208 (33.5%) screened positive for depressive symptoms, while 130 (20.9%) screened positive for anxiety, with 108 (17.4%) screening positive for both. In the sample, 23.8% reported alcohol use, 56.4%, corporal name-calling by caregivers, 78.6% witnessing violence at home and 80.5% bullying at school.

Being in a higher grade in school, alcohol use, use of other drugs and witnessing violence were significantly associated with depression symptoms. Being in a higher grade in school, poorer emotional regulation skills and the use of dagga were significantly associated with anxiety symptoms.

**Conclusion**: These findings add to our understanding of school-going adolescents' pressing mental health needs and suggest that mental health adolescent and parent interventions may be required to address mental health symptoms and associated risk factors.

## Scaling up child and Adolescent mental health services at primary health care level in the Western Cape province of South Africa

#### Dr Stella Mokitimi<sup>1</sup>

<sup>1</sup>Western Cape Department of Health. Khayelitsha Eastern Substructure, Cape Town, South Africa

BIOGRAPHY: Dr Stella Mokitimi is a mental health Program Coordinator at the Western Cape Department of Health, Khayelitsha Eastern Substructure (KESS). She holds a PhD (Psychiatry) from the University of Cape Town. Her PhD work is entitled "Child and adolescent mental health services in the Western Cape of South Africa: policy evaluation, situational analysis, stakeholder perspectives, and implications for health policy implementation". Her Research work has been shared in various platforms, nationally and internationally. She co-supervised an MPhil student on a situational analysis of CAMHS study in one of the African countries. Dr Stella Mokitimi won many awards for her research work in various conference platforms. She has 17years' experience in child and adolescent mental health, working in various platforms: at primary and tertiary level of care. She is a member of the Centre for Autism and Research in Africa (CARA) and the South African Association of Child and Adolescent Psychiatry and Allied professions (SA-ACAPAP). Her mission is to strengthen mental health services and systems, including CAMHSS in low resourced communities in collaboration with various stakeholders in the field and other relevant sectors. She is currently actively collaborating with various stakeholders in her context, on the strengthening of child and adolescent mental health services and systems in the Western Cape Province of South Africa.

**Background:** Child and adolescent mental health services (CAMHS) are neglected globally, with only one in ten children and adolescents receiving treatment from tertiary level of care in low and middle income countries. At primary health care (PHC) and at secondary level of care, CAMHS are under resourced, disorganized, and non-responsive to the needs of the users. This reduces the utilisation of services and perpetuates the psychological trauma on children and adolescents. Khayelitsha Eastern Subdistrict (KESS) experiences similar challenges. The Department of Health in KESS implemented the scaling up CAMHS at PHC level to bridge this gap.

**Methods:** Scaling up started in 2021 and included: the redesign of CAMHS at PHC level, training, and provision of resources. The mental health coordinator consulted with mental health nurses and managers. The mental health nurses were trained on CAMHS. One day a week was allocated for CAMHS in all facilities. Child friendly assessment resources were distributed in facilities. The key indicators: rates inpatient admissions, discharges, PHC visits and first contact with the PHC facilities within 30 days post discharge were used to monitor the impact.

**Results:** The results were: reduced rates of acute admissions, increased rates of discharges, Increased PHC visits and increased first contact at PHC facilities within 30 days post discharge.

**Conclusions:** These findings suggest that scaling up CAMHS at PHC level can potentially reduce the admission rates in acute at secondary level and increase the utilization of PHC CAMHS thereby reducing the negative impact of the exposure to the non-responsive CAMHS at secondary level of care. A systematic review and a qualitative exploration of the user and provider perspectives of the new separate CAMHS may be beneficial to inform practice and policy development and implementation.

### Intellectual Disability Support: Traditional Healers' Views on Collaboration with Western-Trained Healthcare Practitioners

#### Ms Monique Os<sup>1</sup>, Ms Simthandile Witbooi<sup>1</sup>

<sup>1</sup>University of Cape Town, Cape Town, South Africa

**BIOGRAPHY:** Monique Ashtevana Os, currently an Honours student specializing in Psychology at the University of Cape Town, proudly earned her Bachelor of Arts degree in both Psychology and Organizational Psychology. Following her undergraduate success, she pursued an Honours degree in Organizational Psychology in 2022. Monique's outstanding academic performance earned her a place on the University of Cape Town's 2021 Dean's Merit List. Monique dedicated herself to tutoring first and third-year students in both Psychology and Organizational Psychology in 2022 and 2023. In the early stages of her academic career, Monique is exploring her research interests, with a specific focus on indigenous healing practices. Her curiosity extends to child development and holistic healing, indicating a diverse and holistic approach to her studies. As she continues to pursue her academic and research goals, Monique's dedication to psychology is sure to yield valuable insights and positive impacts.

**Introduction:** Impoverished and under-resourced areas such as Khayelitsha, Western Cape have a high prevalence of intellectual disabilities (ID). Caregivers of children with ID, in these communities face immense structural and belief-related barriers to accessing ID biopsychosocial support. Traditional healers can help alleviate these barriers as they are culturally attuned, local language speakers within communities, and are often consulted alone or alongside biomedical professionals. A collaborative and culturally congruent psychoeducation intervention on ID, equipped traditional healers with a biopsychosocial understanding of ID to enhance their ability to serve as support systems in these communities. This study aimed to explore the perspectives of traditional healers on collaboration with Western-trained healthcare workers to provide synergized ID support to families of children with ID – using the intervention as a microcosm for potential future collaborative efforts.

**Methods:** This qualitative study used Bronfenbrenner's Ecological Systems theory as a theoretical framework, a phenomenological methodological approach and thematic analysis to understand and contextualize traditional healers' views on collaboration with western-trained biomedical healthcare practitioners. The study used purposive sampling and conducted semi-structured interviews and a focus group discussion with traditional healers in Khayelitsha, South Africa.

**Results:** The study revealed that divergent healing practices, systemic disparities, and biases towards traditional healers were significant barriers to collaboration. It found that facilitators of collaboration encompassed building rapport, establishing systems for collaboration, increasing access to resources, and promoting community empowerment.

**Conclusion:** Traditional healers viewed collaboration as sensible in the interests of supporting children with ID, but significant challenges are to be addressed. These include bridging the gap in understanding, mitigating negative perceptions and rectifying resource disparities. This research provides valuable insights into the complexities of collaboration and emphasizes the importance of addressing these for synergized ID support in underprivileged communities.

# A demographic and mental health profile of children and adolescents accessing a gender-affirming, gender identity development service in South Africa: A retrospective case series study

<u>Dr Simon Pickstone-Taylor</u><sup>1,2</sup>, Dr Eugene Davidse<sup>1</sup>, Dr Graham De Bever<sup>1</sup>, Professor Petrus De Vries<sup>1</sup> University of Cape Town, Cape Town, South Africa, <sup>2</sup>Neurodiversity Centre, Groot-Drakenstein, South

BIOGRAPHY: General Adult Psychiatrist, and Child & Adolescent Psychiatrist.

He grew up on a farm near Cape Town, South Africa. Did his undergraduate medical degree at Cambridge, finished medicine at University of Cape Town (UCT). Specialised in psychiatry in the USA and finished with a fellowship in Child & Adolescent psychiatry at the University of California San Francisco in 2003. Worked for the National Health Service in the UK for 7 years and then returned to the South Africa in 2011. He works with inmates for the department of correctional services, part time private practice at the Neuro Diversity Centre in the Boland that specializes in Autism Spectrum Disorder.

He has a special interest in Gender Diversity particularly in young people. In 2012 he started the Gender Identity Development Service within UCT's Division of Child & Adolescent Psychiatry, where he provide support for young people up to 18 years old and their families, as well as to other professionals supporting these young people. He is an Honorary Senior Lecturer in the psychiatry department at UCT, and gives training on gender and sexuality to trainees and staff. He is member of the WPATH (World Professional Association of Transgender Health) and founder member of PATHSA (Professional Association of Transgender Health of South Africa).

**Background:** Despite a massive global increase in research on gender diverse youth, particularly from Europe and North America, there have been no studies in Africa.

Aim: To present the first African findings of the demographic and mental health profile of youth who have presented at a gender service in South Africa.

Setting of the study: A specialist mental health out-patient service in state and private for gender diverse youth in the Western Cape.

**Methods:** All consenting youth seen at a gender service in state and by the same clinician in private practice between Jan 2012 and May 2019 were subjects of a retrospective, sequential case series. Data of interest including gender identity and sexuality, mental health history, and social information, was extracted from the psychiatry files of subjects

Results: Thirty-nine (39) subjects were part of the registry and qualified for the study. 72% self-identified as white, 15% as coloured and 13% as black African The rate of co-occurring psychopathology was high (64%) and included high rates of ASD particularly in trans males (26%), suicidal ideation in 31% and a history of suicide attempt(s) in 10%.

**Conclusions:** This first study describing gender diverse youth seeking support relating to their gender identity in Africa, showed they had remarkable similarities to those studied internationally.

**Contribution:** Transgender youth of all races, with similar to demographic profiles found internationally, presented to services in South Africa and are in need of mental health support and interventions. It is important that clincians are aware of the presence of gender diverse youth and their possible demographics and their needs in South Africa and Africa. This is the first study to help them in this area.

### Towards integrated service delivery for children with autism in South Africa

<u>Dr Sarosha Pillay</u><sup>1</sup>, Emeritus Professor Madeleine Duncan, Professor Petrus de Vries <sup>1</sup>University of Cape Town,, South Africa

**BIOGRAPHY:** Dr Sarosha Pillay is a lecturer at the Division of Occupational Therapy at the University of Cape Town where she is the head of the Child Learning, Development and Play (CLDP) cluster. Her research interest is in education systems for children with autism in South Africa. Dr Pillay is a member of the Autism South Africa National Executive Committee.

**Background:** The South African education system is challenged in meeting the educational needs of children with autism and many children are out of schools or inappropriately placed in the system. In this study we performed a whole systems analysis of autism educational services in the Western Cape Province of South Africa to generate recommendations for improved educational service delivery.

**Objectives:** The objectives of the study were to understand the landscape of education systems for children with autism and to generate evidence-based recommendations to strengthen autism educational service delivery.

**Methods:** An exploratory mixed-methods approach was used across two phases. The first quantitative phase described the profile of children with autism in the education system as well as those waiting for educational services. The second qualitative phase examined stakeholder perspectives and recommendations for improved autism service delivery.

Results: Synthesis of findings across the study generated six key actions for service improvements that included a) designing and implementing early intervention programmes, b) developing curricular to accommodate a range of diverse learning needs, c) inclusion of children with autism across the education system, d) creating a dedicated rural inclusive autism plan, e) developing transectoral planning, monitoring and evaluation systems and f) developing integrated policies for autism. Implementation drivers including competency drivers, leadership drivers and organisational drivers could potentially translate these actions into practice for improved autism service delivery.

**Conclusions:** The six actions generated in this study aligns with the Lancet Commission Report on the future of care and clinical research in autism and if implemented could go a long way in improving services for children with autism and their families. Findings from this study may have relevance to other low- and middle-income countries.

## Autism Caregiver Coaching in Africa (ACACIA): Design for a type 1 hybrid effectiveness-implementation trial

Ms Marisa Viljoen<sup>1</sup>, Dr Lauren Franz<sup>1,2,3</sup>, Mrs Musaddiqah Brown<sup>1</sup>, <u>Ms Katlego Sebolai</u><sup>1</sup>, Ms Noleen Seris<sup>1</sup>, Dr Nokuthula Shabalala<sup>1</sup>, Professor Petrus J de Vries<sup>1</sup>

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**BIOGRAPHY:** Marisa is an occupational therapist, PhD candidate in Neuroscience and project coordinator for the ACACIA project at the University of Cape Town. ACACIA (Autism Caregiver Coaching in Africa) is an early autism intervention study that aims to provide access to evidence-based autism services for families in underserved areas. Her PhD research explores the use of telehealth for to delivery autism intervention in low-resource communities.

**Introduction:** Global gaps in early autism intervention are particularly clear in Africa, where 40% of the world's children will live by 2050. Early autism intervention can significantly improve outcomes. A key implementation strategy to address the scarcity of specialists in Africa is task-sharing early intervention to non-specialists. Naturalistic Developmental Behavioural Interventions (NDBI) are a class of early autism intervention that can be delivered by caregivers. To address the early intervention gap, we adapted a non-specialist delivered caregiver coaching NDBI for the South African context, and pre-piloted this cascaded task-sharing approach within an existing system of care.

**Methods:** We will test the effectiveness of the caregiver coaching NDBI compared to usual care and describe factors that impact coaching implementation within the Western Cape Education Department (WCED). This is a type 1 effectiveness-implementation hybrid design using an assessor-blinded, group randomized controlled design. rial. Participants include 150 autistic children (18-72 months) and their caregivers who live in Cape Town, South Africa, as well as those involved in intervention implementation. Early Childhood Development practitioners employed by the WCED will deliver 12, one-hour, coaching sessions to the intervention group. The control group will receive usual care. Distal co-primary outcomes include the Communication Domain Standard Score (Vineland Adaptive Behaviour Scales, Third Edition) and the Language and Communication Developmental Quotient (Griffiths Scales of Child Development, Third Edition). Proximal secondary outcomes include caregiver strategies measured by the sum of five items from the Joint Engagement Rating Inventory. We will describe key implementation determinants.

**Results:** Participant enrolment started in April 2023 and will be completed by March 2027. We will present the trial design and provide project updates.

**Conclusion:** The ACACIA trial will determine whether a cascaded task-sharing intervention delivered in an educational setting contributes to significant/notable improvements in communication of autistic children and identify implementation barriers and facilitators.

### Mapping the child and adolescent mental health landscape in South Africa: an electronic survey

<u>Dr Simphiwe Simelane</u><sup>1</sup>, Professor Petrus de Vries<sup>1</sup>
<sup>1</sup>Universitry of Cape Town, Cape Town, South Africa

**BIOGRAPHY:** Simphiwe Simelane is a PhD student at the Centre for Autism Research in Africa at the University of Cape Town. She qualified as a medical doctor in 2016 and completed her internship and community service thereafter. She is an SAMRC Clinician Researcher Programme and UCT Accelerated Transformation Programme scholar. Her experience as a junior doctor has driven her passion for her research interests which include health systems, health policy implementation and mental health. Her PhD project focuses on strengthening child and adolescent mental health services and systems in South Africa.

**Background:** Child and adolescent mental health services and systems (CAMHSS) play a critical role in addressing the mental health needs of young people. However, recent regional studies of the landscape of the CAMHSS show that there has been limited improvement in CAMHSS in South Africa.

**Aim:** This study aimed to 1) determine if findings from a 2016/2017 Western Cape research study which described the landscape of CAMHSS in the Western Cape were still relevant in the Western Cape and if they were similar in other South African provinces, and 2) seek priorities for CAMHSS strengthening from participants.

Setting: The study included child and adolescent mental health service providers from all nine provinces of South Africa.

**Methods:** Using an electronic, cross-sectional survey, data were collected from CAMHSS service providers through a Likert questionnaire an open-ended question. Survey data, collected from January to November 2022, were compared to previous research findings from the Western Cape to assess relevancy and applicability, and priorities for strengthening CAMHSS were identified.

**Results:** The findings suggest that issues identified in the 2016/2017 Western Cape research study remain relevant and similar challenges exist across other South African provinces. Service providers expressed the need to prioritise increased resources, decentralization of care, capacity building, and multisectoral approaches, among others.

**Conclusion and Contribution:** Despite the high burden of mental illness among children and adolescents in South Africa, there has been little progress in strengthening CAMHSS. This study underscores the need for participatory approaches to develop proactive efforts in addressing the systemic challenges in CAMHSS.

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**Conclusion and Contribution:** Despite the high burden of mental illness among children and adolescents in South Africa, there has been little progress in strengthening CAMHSS. The study underscores the need for participatory approaches to develop proactive efforts in addressing the systemic challenges in CAMHSS.

### Temporality and the re-evaluation of memories in aging child Holocaust survivors: a developmental trajectory

#### **Prof Cora Smith**<sup>1</sup>

<sup>1</sup>University of the Witwaterrand, Johannesburg, South Africa, <sup>2</sup>Charlotte Maxeke Johannesburg Academic Hospital, Johannesburg, South Africa

**BIOGRAPHY:** Prof C. Smith is an Adjunct Professor in the Division of Psychology in the Department of Psychiatry at the University of the Witwatersrand. She also holds a joint appointment post as the Chief Clinical Psychologist at Child, Adolescent and Family Unit, Johannesburg Hospital. She runs the CAFU Family Therapy Programme and teaches Trauma Counselling and Individual Psychotherapy with children, adolescents and parents. Her interests are in the development of personality pathology through the life cycle with a particular focus on attachment and trauma. She has a keen interest in the ethical dilemmas that emerge in clinical practice. She is responsible for the training of MA Clinical Psychology Interns, as well as training of Child Psychiatry Specialists, Neurodevelopmental Paediatricians and Psychiatric Registrars in psychotherapy. She holds a Masters in Clinical Psychology and a PhD from the University of the Witwatersrand.

She currently serves on the Human Ethics Research Committee -Medical at the University of the Witwatersrand. She previously served on the Ethics Advisory Subcommittee of the S.A. School Psychologist's Association, the Ethic's Advisory of Educational Psychologists of SA and the Ethics Advisory Committee of the South African Psychoanalytic Confederation. She is the co-editor of 2 books; book Psychodynamic Psychotherapy in South Africa: contexts, theories and applications, published in 2014 and "Catastrophic Grief, Trauma and Resilience in child concentration camp survivors. A retrospective view of their holocaust experiences, published in 2023.

This paper is based on a chapter written by Cora Smith in a book entitled: "Catastrophic Grief, Trauma and Resilience in child concentration camp survivors. A retrospective view of their holocaust experiences. The book is co-authored by Tracey Farber, Gillian Eagle and Cora Smith and was published by Academic Studies Press in June 2023.

The book is based on the qualitative research of 10 child Holocaust survivors (one never spoke). The research entails thematic content analyses describing the in-depth narratives of child holocaust survivors and their experiences of complex trauma, complicated bereavement, ageing, resilience and existential loneliness. The work is unique in that it describes the trauma of child Holocaust survivors who were placed in concentration camps. Most children were killed on entry. Child survivors were rare. These survivors went on to build lives with considerable resilience and coping but their trauma remained within for the next 70-75 years. This is a unique view of the impact of catastrophic trauma and grief over a lifespan.

The specific paper being presented addresses the impact of temporality on the re-evaluation of memories in aging survivors. Temporality became a major component of the aging survivors' narratives as they re-evaluated their traumatic life experiences from ever advancing developmental positions. Survivors differed in their focus on Holocaust events as they aged, and their developmental perspectives often changed their views and sometimes even their emotional responses. This paper focuses on the impact of the passage of time on the reappraisal of traumatic events experienced by child survivors.

How these experiences contributed to a re-storying of their life narratives and promoted a sense of survival and mastery in some and a sense of despair and helplessness in others as each navigated the developmental stage of old age is discussed.

## "A turn in the road, but still a rough journey" - Parent and child perspectives of outcomes after pre-adolescent inpatient psychiatric admission

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UCT, Cape Town, South Africa

#### **BIOGRAPHY:**

Master's Degree in Psychiatry UCT 2022 Professional Nurse at psychiatric inpatient unit Red Cross Hospital Cape Town 2004 - 2017 School Nurse at Vista Nova High School Cape Town since 2018

**Introduction:** Research on outcomes of child and adolescent psychiatric inpatients appears insufficient and neglected. Where data are available, the majority of studies focus on outcomes in adolescents. This study aimed a) to describe child and parental perspectives of short-, medium- and long-term outcomes of children who have had a pre-adolescent inpatient psychiatric admission, and b) to analyse these dyadic experiential data to identify outcome variables of importance to families and service users that could be used in future outcomes-based research.

**Methods:** The study employed a qualitative methodology, using semi-structured in-depth interviews of ten parent-child dyads to (a) collect the perspectives of children who have had an inpatient psychiatric admission at a pre-adolescent unit and their parents, and (b) to analyse the experiences of inpatient admission and perceived outcomes after discharge using thematic analysis.

**Results:** Overall, inpatient psychiatric admission was viewed as a positive and empowering experience by parents and children. Clear short-term benefits were reported as a result of new diagnoses, medications and new skills gained through the admission process. More than half of parent-child dyads reported long-term benefits, but many families commented on ongoing challenges. Thematic analysis identified diagnostic certainty, acquisition of cognitive and behavioural skills, appropriate educational environment, peer relationships, sustained follow-up and medication management, and parent-child relationships, as important contributors to outcomes. Importantly, the presence or lack of these elements influenced outcomes.

**Conclusions:** The study explored parent-child dyadic perspectives about their experiences of inpatient mental health admissions for pre-adolescents and perceived outcomes after admission. The majority of families found inpatient admission positive and helpful, and thematic analysis identified a number of functional variables that may predict outcome. However, positive outcomes were associated with ongoing difficulties over time, as indicated by the theme "a turn in the road, but still a rough journey".

### The multisystemic roots of adolescent and emerging adult resilience to depression

<u>Prof Linda Theron</u><sup>1</sup>, Dr Jan Höltge<sup>2</sup>, Dr Kate Cockcroft<sup>3</sup>, Dr Ansie Fouche<sup>4</sup>, Dr Michael Ungar<sup>2</sup>

<sup>1</sup>University of Pretoria, Pretoria, South Africa, <sup>2</sup>Dalhousie University, Canada, <sup>3</sup>University of the Witwatersrand, South Africa, <sup>4</sup>United Arab Emirates University, United Arab Emirates

The purpose of this paper is to challenge mono-systemic understandings of what supports resilience to depression. Using a multisystemic resilience framework, and drawing on quantitative and qualitative data generated iteratively by adolescents (data collection: May 2020 to December 2021; n = 223; mean age: 17.16 years, SD = 1.73) and emerging adults (data collection: 2021; n = 233; mean age: 24.63, SD: 2.43), this paper shows that multiple resources from multiple systems (i.e., biological, psychological, social, and physical ecological systems) characterised the resilience of both young people reporting high risk and minimal symptoms of depression at a point in time and over time. In contrast, those reporting high risk and elevated symptoms of depression at a point in time and over time reported single system resources or limited resource combinations. The paper concludes with pointers for child and adolescent mental health professionals wishing to maximise young people's capacity for resilience to depression.

### From Empilweni, Khayelitsha, to Transcultural Centre for refugees, Stavanger, Norway. Lessons learned in South Africa

#### Dr Aina Basilier Vaage<sup>1</sup>

<sup>1</sup>Transcultural Centre for Refugees, Stavanger, Norway

**BIOGRAPHY:** Medical doctor, senior consultant psychiatrist and child- and adolescent psychiatrist, Ph.D. Title of the thesis: «Mental health of Vietnamese refugees. Long-term and trans-generational perspectives».

Theme of main interest: Transcultural psychiatry/child-psychiatry.

Examples of inspiration and models from South-Africa will be given.

Head of Department of child psychiatry at Stavanger University hospital (SUS) for five years (1994-1999), later senior consultant child psychiatrist and researcher at SUS (2000 – 2020). From 2010 to 2014 she established and headed a refugee-child project at a large asylum-centre. From 2014 to 2020 she was a senior consultant at the Transcultural Centre for traumatized refugees at SUS. After retirement, Vaage established «Vaage's transcultural psychiatric services», giving lectures and working as an expert in cases for the county social welfare boards. These boards are responsible for decision-making with regard to child welfare services, and Vaage is giving advice in cases related to refugee-families.

She has received two honorary degrees and also The King's Medal of Merit for her work with refugees.

**Introduction:** As a senior consultant child-psychiatrist I visited Cape Town three times in 1998-2001, meeting SouthAfrican colleagues working in challenging situations (Swartz, 1998). This made a great impact on me. Several lessons learned were important in the establishment of, first, a refugee-child project in Norway's largest asylum centre (Vaage, 2014), and later, in the establishment of the first, and still only, Transcultural Centre for traumatized refugees and asylumseekers in Norway (Bäärnhielm, Mösko, Vaage 2021).

**Methods:** Clinical psychiatric work with vulnerable groups as refugees are challenging, by the lack of cultural evidence in research, in addition to referral barriers representered by stigma and taboo.

Results: In the late 1990-ies, the Department of Child- and adolescent mental health in Stavanger, Norway, was struggling to keep the waiting-list manageable, with therapists having three to five consultations a day, the waiting-list several months long. Experiences from SouthAfrica were important in changing our work focus. Today the Transcultural centre is working in a different way, with a small psychiatric out-patient clinic and focus on supervision of those meeting the refugees on a daily basis. Barriers for referral to mental health services due to stigma and taboo are addressed. Areaflexibility in our work is of outmost importance. Refugees are meeting public health nurses and other helpers in an arena that for them represents safety, and therefore building trust, in close cooperation with therapists from our centre. Transcultural child psychiatric methods are different from psychiatry as usual, as it is focusing on context and explanatory models.

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**Conclusion:** Colleagues in Cape Town shared their way of dealing with an immensely growing caseload after the end of apartheid. This inspired me and colleagues in rethinking our way of working in Stavanger.

### The Effect of the COVID-19 Pandemic on the mental health of occupational therapists and children due to changes in service delivery

#### Dr Janine van der Linde<sup>1</sup>

<sup>1</sup>University of the Witwatersrand, Parktown, South Africa

**BIOGRAPHY:** I'm an occupational therapist with more than 25 years' experience in pediatrics and mental health for children and adolescents. I have a PhD with a special interest in sensory integration theory and its application for clients from disadvantaged areas. My research focuses on the provision of services in pediatric OT, ADHD, autism, and community pediatrics.

I work as a lecturer in pediatric OT at the University of the Witwatersrand and have a passion for training students to provide appropriate intervention to children.

The COVID-19 pandemic resulted in a lasting impact on the delivery of healthcare services across the world, including occupational therapy services for children. The closure or poor continuation of occupational therapy services during this period added additional stress to children who were already at risk of developmental and mental health difficulties. The pandemic not only impacted the mental health of the children but also the occupational therapists providing intervention for children with difficulties. This study aimed to determine how the COVID-19 pandemic restrictions affected pediatric occupational therapists and their service delivery for children.

A cross-sectional descriptive design was used to obtain both narrative and descriptive data through a self-administered electronic questionnaire. Questionnaires were completed by occupational therapy practitioners who treated pediatric patients during COVID-19 lockdown restrictions. Descriptive statistics were used to summarize the data, with additional qualitative content analysis to identify key themes and categories.

An increase was seen in anxiety in both the children and occupational therapists. Occupational therapists within both private and public healthcare settings indicated that their mental health was impacted, resulting in difficulty in providing services to children. Ninety-eight percent of the occupational therapists indicated that lockdown restrictions resulted in frustration, anxiety, and compassion fatigue.

Practitioners were unable to provide occupational therapy services to children at risk, resulting in increased anxiety for both the child and the occupational therapist. There was a decrease in patient attendance for intervention due to fear and increased anxiety in the children during this period. Practitioners reported the pandemic affected not only the children's mental health but also their own emotional state, both positively and negatively. Across different levels of service delivery, many practitioners experienced loss of income, changed worked hours (longer or fewer), and decreased use of parents to deliver therapeutic services.

# Using telehealth to coach caregivers of young autistic children in South Africa implementation outcomes and caregiver-child signals of change

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**BIOGRAPHY:** Marisa is an occupational therapist, PhD candidate in Neuroscience and project coordinator for the ACACIA project at the University of Cape Town. ACACIA (Autism Caregiver Coaching in Africa) is an early autism intervention study that aims to provide access to evidence-based autism services for families in underserved areas. Her PhD research explores the use of telehealth for to delivery autism intervention in low-resource communities.

**Introduction:** While telehealth can meet service needs of families in under-served, low-resource areas of South Africa, the digital divide can reinforce existing access disparities. It is therefore critical to consider cost and feasibility when developing telehealth interventions. We adapted a Naturalistic Developmental Behavioural Intervention (NDBI)-informed caregiver coaching intervention for telehealth-delivery in Cape Town, South Africa. We examine implementation outcomes (acceptability, feasibility, and appropriateness) and signals of change in autistic children and their caregivers following 12, 1-hour long sessions of telehealth NDBI-informed coaching delivered by non-specialists over smartphones.

**Methods:** Data from in-depth interviews and quantitative measures on implementation outcomes were analyzed using directed content analysis and descriptive statistics respectively. A single-arm pre-post design assessed caregiver and child signals of change. Change over time will be displayed as tabular and graphical summaries. Outcomes included implementation fidelity, behaviours assessed using the Joint Activity Rating Inventory (JERI), and child adaptive behaviour measured on the Vineland Adaptive Behaviour Scales (VABS-3). Quantitative analyses were conducted using SPSS statistics.

**Results:** Telehealth-coaching was described as acceptable, appropriate, and feasible by participants. Quantitative measures supported these findings (Acceptability of Intervention Measure=4.25/5, Intervention Appropriateness Measure=4.47/5, and Feasibility of Intervention Measure=4.14/5).

Caregiver implementation fidelity increased for 7 of 9 of caregivers between T1 (median [IQR]: 55 [18.5]) and T2 (median [IQR]:68[24.5]). Signals of change were observed in the following JERI items: child supported joint engagement, child responsiveness to caregiver's communication, and fluency and connectedness. VABS-3 communication scores increased significantly (p=0.049) between T1 (median[IQR]: 34[27]) and T2 (median [IQR]:40[25.5]). Individual VABS communication scores increased for 7 of 9 caregivers. Findings were supported by qualitative data.

**Conclusion:** Results indicate a good fit between contextually-adapted telehealth caregiver coaching and the South African setting. Signals of change in both children and caregivers provide early evidence for the feasibility of telehealth-delivered caregiver coaching implemented by non-specialists.

### Addressing Praxis Difficulties to Alleviate Anxiety in a Paediatric Case Study

#### Mrs Emma Wijnberg

<sup>1</sup>South African Institute for Sensory Integration, Hilton, South Africa

**BIOGRAPHY:** Emma is an Occupational Therapist in paediatric private practice, who serves on the board for the South African Institute for Sensory Integration She is passionate about discovering and developing an understanding for individual abilities and empowering professionals in providing evidence-based and effective intervention.

Emma is a devout advocate for Sensory Integration and is passionate about creating an understanding for the relevance of SI, amongst professions.

Emma regularly presents workshops, for parents and professionals, online and in person, on various topics pertaining to parenting, early intervention, neurodiversity, play and sensory processing.

**Introduction:** Occupational Therapy in childhood focusses on all aspects of a child's participation in life – including school, play, and activities of daily living. Mental health difficulties as well as physical challenges can influence this significantly. A young child was referred to Occupational Therapy with concerns related to pronounced anxiety and perfectionist tendencies. While anxiety-focused interventions were employed in therapy, unforeseen challenges emerged, leading to the exploration of sensory integration and praxis difficulties as a differential diagnosis and reason underpinning his difficulties.

**Methods:** A single case study is described, where the therapist administered the Sensory Integration and Praxis Test to assess the child. This revealed significant sensory vulnerabilities and praxis deficits, limiting his ability to elicit anticipatory responses to novel challenges. Careful observations and analysis of his patterns of behaviour were made in understanding the child and choosing a path of effective treatment.

**Results:** Coping mechanisms of practicing specific skills repetitively to counter anxiety triggers were noted. This assisted the child in avoiding the need for anticipatory responses by attempting to eliminate any novel situations encountered. Any unpredictable or novel situations triggered significant anxiety, as the child was not able to generate anticipatory responses due to his identified sensory integration and praxis difficulties. Sensory integration therapy was initiated to target praxis vulnerabilities. As sensory integration and praxis challenges were addressed, an alleviation of the child's anxiety symptoms was observed both in therapy, at home and at school.

**Conclusion:** The therapeutic progress showcased the intricate link between sensory processing deficits and anxiety. The child's reliance on repetitive practiced actions lessened as sensory integration improved, highlighting the therapeutic potential of this integrated approach. This underscores the reciprocal influences of sensory integration difficulties and anxiety in children. This emphasises the importance of holistic interventions to comprehensively address paediatric mental health concerns.

### Bullying in schools: A growing scourge of violence. Do we have legislation that informs intervention?

#### Mr Clive Willows<sup>1</sup>

<sup>1</sup>Private Practice, Pietermaritzburg, South Africa

BIOGRAPHY: Clinical Psychologist in Private Practice with an interest in Psycho-legal work.

Bullying in schools is widespread and has been a feature in many childhoods for generations. In a number of instances it has been considered acceptable and condoned through traditional practices in educational institutions. Viewed within the context of the prevalence of interpersonal violence in South Africa the traditional acceptance of bullying should no longer be tolerated. A relatively recent phenomenon has been the use of social media and digital communication to target individuals with verbal humiliation. The use of videos to distribute scenes of violence in schools provides a disturbing insight into the glorification and acceptance of bullying thus perpetuating a view of violence being "acceptable".

Bullying has been found to have profound effects on victims leading to depression, anxiety and poor self-esteem. These consequences occur during critical stages of human development and are known to have lifelong effects. It has also been a feature identified in the causality of an increasing number of suicide attempts in children and adolescents.

This presentation looks at how current legislation can be applied to incidents of bullying and how intervention can be legitimately applied. It is evident that this legislation can have the dual benefits of protecting victims as well as intervening with perpetrators. It is possible that correct interventions with perpetrators may contribute to preventing further abuse during their adult years. Legislation does exist and could be effectively applied in drafting national policy for all educational institutions. Such legislation correlates with psychological principles for treatment and prevention, and these interventions should be structured within this legal framework.

### The application of theory and research when recommending care and contact arrangements for infant children of separated parents.

#### Mr Clive Willows<sup>1</sup>

<sup>1</sup>Clinical Practitioner in Private Practice, Pietermaritzburg, South Africa

BIOGRAPHY: Clinical Psychologist in Private Practice with an interest in psycho-legal work.

**Introduction:** Recent trends in relationship breakdowns indicate an increase in the frequency of separations relatively early in the relationship history. A consequence is an increasing need to provide recommendations for the care and contact arrangements for infants. This presentation draws on the well documented theory and research regarding early attachment.

It will be argued that the consistent conclusions of this body of research should be a priority consideration when such recommendations are submitted.

**Results from research:** The extensive research into different attachment styles of infants began in the 1950's and has produced consistent findings. More recent research has confirmed John Bowlby's contention that attachment styles are evident "from the cradle to the grave".

These findings should therefore challenge recommendations regarding infant care and contact arrangements that may result in insecure attachment. In a country plagued with a high incidence of gender based violence, sexual assault and the abuse of children we would be negligent if we ignore the direct link between infant attachment styles and later behaviours associated with adult Cluster B personality disorders.

**Conclusion:** It is necessary to establish those factors which either promote secure attachments or facilitate the risk factors that promote adult personality frailties. These risk and protective factors should be identified and clarified through careful, diligent research and we recognise that there is currently a deficiency of research in this area.

In recognition of the theme of the Congress to build relevant evidence and solutions for the future, it is strongly advocated that this issue is addressed through collaborative conferencing of the significant role players empowered with the responsibility of providing recommendations for infants at the center of custody disputes.

### Assessment of the Impact of a South African Caregiver Coaching Early Autism Intervention on Caregiver Stress: A Mixed-Methods Study

Ms Maame-Animwah Amoako, Marisa Viljoen, Katlego Sebolai, Musaddiqah Brown, Nokuthula Shabalala, Noleen Seris, Lauren Franz, Petrus J de Vries

<sup>1</sup>Duke Center for Autism and Brain Development, Division of Child and Adolescent Psychiatry, Department of Psychiatry and Behavioral Sciences, Duke University, Durham, United States, <sup>2</sup>Duke Global Health Institute, Duke University, Durham, United States, <sup>3</sup>Centre for Autism Research in Africa (CARA), Division of Child & Adolescent Psychiatry, Department of Psychiatryand Mental Health, University of Cape Town, Cape Town, South Africa, <sup>4</sup>Department of Biostatistics and Bioinformatics, Duke University, Durham, United States

BIOGRAPHY: Maame Amoako is a third year medical student at the Duke University School of Medicine in North Carolina, US. She is working under the mentorship and support of Dr. Lauren Franz during her research year at Duke. She studied Health Sciences and Global Health during her undergraduate education in Boston, US at Northeastern University. Her research pursuits in her undergraduate education included work on understanding the healthcare system in Ghana, the improvement of healthcare for children in Ghana, research on the health disparities within the COVID pandemic emergence, and research in creating an interactive learning environment for health care professionals to understand the importance of treating diverse populations in medicine. Her current engagements include leadership as president of the Student National Medical Association and the Pediatrics Interest Group at Duke. She continues to engage women's health advocacy with the Black Maternal Health Equity Initiative and group prenatal care classes. Maame's present research focuses include work with the Duke Obstetrics and Gynecology Department to understand the impacts of mental health on postpartum health and breastfeeding, work in creating a new surface anatomy atlas to incorporate different skin tones and body types to enhance medical education, and present work in understanding caregiver coaching for parents of children with autism in South Africa. Maame is passionate about equitable health for women and children, the improvement of healthcare systems, and the mitigation of health disparities for minority groups around the globe through patient and family advocacy, research, and sustainable implementation.

**Introduction:** While caregiver coaching can teach caregivers early intervention strategies that they can use with their young autistic child during everyday activities, there is limited access to caregiver coaching in low-resource, culturally and linguistically diverse communities – a significant implementation gap. Because caregivers play a pivotal role in early intervention, it is important that the transactional process by which caregivers can both impact early intervention outcomes and be impacted by the intervention itself be understood. We hypothesize that caregiver stress will be mitigated through caregiver coaching, but response may be impacted by contextual factors such as poverty, limited resources, and limited social support. We further hypothesize that some questions used to measure caregiver stress may require contextual adaptation.

**Methods:** We will utilize a mixed methods approach to assess how caregiver coaching impacts caregiver stress in caregivers of young autistic children who live in South Africa. We will collect quantitative data on caregiver stress by administering the Parenting Stress Index-Short Form (PSI-SF) pre-and-post 12, 1-hour caregiver coaching sessions in caregivers (n=30) participating in a coaching intervention. Pre-post summary statistics (median and IQR) will be calculated. We will then review this quantitative data through team discussion, to identify PSI-SF questions that may require contextual adaptation. We will utilize the think-aloud method of cognitive interviewing with probes to explore potentially problematic PSI-SF questions with an additional 10 caregivers enrolled in the coaching intervention. Qualitative data will be analyzed using directed content analysis.

**Results:** Participant enrollment for the quantitative aspect of this project began in April 2023. Participant enrollment for qualitative data will take place in January 2024. Quantitative PSI-SF results and qualitative cognitive interview results will be presented.

**Conclusion:** This study will explore whether caregiver stress is mitigated through caregiver coaching. In addition, it will delineate whether the PSI-SF requires contextual adaptation.

### Improving awareness and access to Mental Health Care for all children from underprivileged areas

<u>Mrs Ronel Aylward</u><sup>1</sup>, Prof Renata Schoeman, Ms Claire Tobin, Ms Marguerette Osborne, Ms Miche Moodley, Ms Joanne Beley <sup>1</sup>Goldiclocks and the Bear Foundation, Cape Town, South Africa

**BIOGRAPHY:** Registered as nurse in General nursing, Midwifery at Sandton Hospital and Psychiatry at Stikland hospital. After qualifying in Psychiatry I work for 3 years in psychiatry, enjoying the Children's Ward. I complete my Nursing Administration and Community health at Stellenbosch University. I was appointed a Unit Manager in a private hospitals group for 28 years. I complete a business cours, NQF at Netcare Mill park business school in 2006. I have completed various courses in Conflict Management, Coaching, Resilience Training and Human Resources on the disciplinary process. I started at Goldilocks and the Bear Foundation in January 2023

Goldilocks and the Bear Foundation is a nonprofit organisation which focuses on attention deficit/hyperactivity disorder (ADHD) and other mental health difficulties. We provide free ADHD and mental health screening, and early intervention for children in underprivileged communities. Many children that suffer from (ADHD) remain undiagnosed. Through the Foundation's presence in the communities, we aim to improve mental health care awareness. Goldilocks and the Bear Foundation aims to remove barriers to education and in doing so improve the quality of life and opportunities for children in underprivileged/impoverished communities. The Foundation assists in bridging this gap by creating awareness and early intervention, by providing training to parents and teachers.

Barriers to accessing mental health support include difficulties in identifying and communicating distress, stigmatizing beliefs, shame, a preference for self-reliance, and that help will be difficult to access. There is no clear reason why some children develop mental health issues. Being exposed to traumatic experiences can make it more likely.

**Method:** Collateral information is obtained from teachers, parents, and social workers. We gather our statistics from this information. A detailed database was built. Each client is allocated a unique Goldilocks and the Bear Foundation number to be used for future reference. The process will be explained.

**Results:** Through our statistical analysis, out of 1645 children screened, we identified 629 with ADHD, 465 with possible ADHD, 112 with learning difficulties, and 220 with anxiety or depression. 3059 referrals were made to various volunteers (healthcare professionals) as well as clinic referrals.

**Conclusion:** While mental health clinics are available in the public sector, many children with ADHD fail to reach the stage of diagnosis and treatment because of insufficient awareness and information within their communities. By providing training and early intervention we can ensure better access to mental healthcare for children from underprivileged communities.

### Exploring the unique mental health challenges faced by gifted children and the appropriate support they require.

#### Mrs Kirsty Beamish 1, 2

<sup>1</sup>Private Practice,, South Africa, <sup>2</sup>University of Cape Town (UCT), Cape Town, South Africa

BIOGRAPHY: Kirsty Beamish obtained her Occupational Therapy degree from UCT in 2001.

After graduating she travelled to Sweden to present a paper at the World Federation of Occupational Therapists based on her thesis regarding the importance of play in a child's life. She then moved to the UK where she worked in both social services and hospital settings. Kirsty has always had a keen interest in working with children and in 2003 moved back to South Africa to start working in a private paediatric practice, before opening her own private paediatric practice in 2011. During this time she has gained much experience in a variety of areas including learning difficulties, concentration difficulties, emotional and behavioural difficulties, sensory difficulties, autism and other developmental delays. Kirsty has a special interest in Gifted Children, and the impact this has on both the child and the family unit. She has become aware of how little knowledge and support is available to parents, and gifted individuals, in South Africa and as a result has begun her Masters journey with a specific focus on gifted children and individuals, the challenges they experience, and the support that is needed in order to help these individuals reach eminence in adulthood. Kirsty is married and is a mother to 2 gifted children.

Gifted children often exhibit advanced intellectual abilities but they also grapple with heightened sensitivities, perfectionism, social isolation, and asynchronous development. All of which can lead to anxiety, depression, and feelings of inadequacy. To effectively support gifted children's mental well-being, early identification and a holistic approach is crucial; and requires collaboration between parents, educators and a variety of health professionals to provide a nurturing environment that fosters the development of coping mechanisms, social skills, and a healthy self-concept for gifted children.

This presentation will highlight the common mental health issues experienced by gifted children, the importance of early identification and will examine the protective factors and interventions that can promote positive mental health outcomes for gifted children. It will also touch on the need for increased awareness in order to advocate for and ensure that the gifted child's mental health needs are supported and met. Further research and interventions within our South African context are essential to empower gifted children to thrive and contribute positively to society.

### Caregivers' experiences of weaning their children from ADHD medication

Ms Casey Botha<sup>1</sup>, Dr Leigh Tucker<sup>1</sup>, Prof Kelvin Mwaba<sup>1</sup>
University of the Western Cape, Cape Town, South Africa

**BIOGRAPHY:** The presenter completed her Masters in Research Psychology at the University of the Western Cape, is registered with the Health Professions Council of South Africa (HPCSA) as a Research psychologist. Her background includes research on substance use, quality of life, ADHD, resilience and emerging adulthood.

**Introduction:** Attention-deficit/hyperactivity disorder (ADHD) is a neurodevelopmental disorder characterised by levels of inattention and/or increased hyperactivity/impulsivity. Medications have been widely used as an effective ADHD treatment for many years. Despite the benefits of medication, many caregivers are hesitant when it comes to starting and continuing ADHD medication. The aim of this research project was to explore caregivers' experiences of weaning their children from ADHD medication. An exploratory research design was employed to explore caregivers' experiences of weaning their children from ADHD medication and the impact of the discontinuation of medication on family functioning.

**Methods:** A qualitative methodological framework was utilised. Purposive sampling and snowball sampling were used to recruit caregiver participants. The data collected were analysed using thematic analysis. Ethics guidelines as specified by the Humanities and Social Sciences Research Ethics Committee at the University of the Western Cape (UWC) were followed;

**Results:** The study determined that caregivers discontinued their child's ADHD medication due to the negative experiences associated with the medication. The rationale for discontinuation of medication was attributed to the side effects observed, family judgement regarding ADHD as a legitimate disorder, fears of substance dependence, as well as caregivers wanting their children to reach their true potential without using medication. It was also found that the discontinuation of medication negatively impacted family functioning and increased conflict and stress within the family. It also required additional hard work from the parents;

**Conclusion:** All caregivers had one thing in common — discontinuing the medication was in the best interest of the child and finding an alternative method that would suit the child, even if it meant more responsibility for the caregivers.

### Considering sensory integrative disorders as a possible reason for oppositional behaviour

#### Mrs Ray Anne Cook<sup>2</sup>, Mrs Gina Rencken<sup>1</sup>

<sup>1</sup>SAISI & University of Kwazulu Natal, Assegay, South Africa, <sup>2</sup>SAISI, , South Africa

**BIOGRAPHY:** Gina Rencken is an Occupational Therapist with a special interest in sensory integration, neurodevelopmental therapy and early intervention. She currently works at UKZN where she is responsible for the paediatric content in the curriculum. She is currently finishing up a PhD, looking at the neurobehavioural functioning of infants born to mothers seropositive to HIV. Gina is a board member of the South African Institute for Sensory Integration (SAISI), as well as the council chair for the International Council of Educators in Ayres Sensory Integration (ICE-ASI). She has presented at congresses nationally and internationally in the fields of Occupational Therapy related to Paediatrics, Ayres Sensory Integration, Paediatric Neurology, Infant and child mental health, maternal mental health, and Early Intervention.

Sensory Integration is understood as an unconscious process in which the brain organises sensations from the internal and external environment for use - allowing a person to respond and act in a purposeful manner. This "purposeful manner" is generally accepted as being socially acceptable behaviour, needed to successfully meet the demands of a task in that moment. Sensory integrative disorders or dysfunctions indicate a disruption in this process and may be observed in difficulty reacting to sensory input in an appropriate manner, which may be observed as irritability and reactive behaviour. Children with sensory integrative difficulties also often have difficulty organising their behaviour, and may not do what is expected of them in social situations. Oppositional defiant disorder shares many of these behavioural manifestations, with difficulty in self-control of emotions and behaviours, disruptive or defiant behaviour, and irritable mood. Oppositional defiant disorder as a diagnosis has more stigma attached and may have a further negative impact on a child's mental health and occupational performance in school, play and activities of daily living.

In this presentation, the similarities and differences of the disorders are considered from an Occupational Therapy point of view. Assessment tools and processes are discussed as well as potential non-pharmacological management through ayres sensory integration. The case for considering a sensory integrative difficulty as a differential diagnosis in part of the holistic management of a child with behavioural difficulties using appropriate, sensitive standardised testing is made.

### Adolescent voices in research: The experiences of participation in health research

#### Prof Eugene Lee Davids<sup>1</sup>

<sup>1</sup>Department of Health Studies, University Of South Africa,, South Africa

**BIOGRAPHY:** Eugene Lee Davids is a Senior Lecturer in the Department of Health Studies at the University of South Africa as well as an Extraordinary Professor at the Optentia Research Unit, North West University. His research focused on adolescent and emerging adult health.

**Introduction:** Engaging adolescents and empowering them is possible through participation in health research about matters that concern their health and well-being. Adolescent participation assists in providing an opportunity to be heard and to identify matters that they view as important and providing possible solutions to their participation in research. The current study therefore aimed to examine the experiences of adolescent participation in a health research study.

**Methods:** The study employed a qualitative descriptive approach. Data were generated using semi-structured interviews among 16 adolescents from two secondary schools in the Western Cape, South Africa. All interviews were transcribed and analysed using thematic analysis.

**Results:** The analysis of the semi-structured interviews identified X major themes. The themes included: (i) characteristics of interviewers that made adolescents comfortable sharing their experiences, (ii) adolescents feeling their voices are heard through participation, (iii) adolescents awareness of decisions and decision-making and (iv) an opportunity to practice decision-making.

**Conclusion:** The results in the current study provide insights into the experiences of adolescents being participants in a health research study. The results provide an opportunity for the voices, experiences and perspectives of adolescents to be valued and to be considered when making decisions about adolescent-focused policies, programmes and interventions.

# A proposed quality of life practice model for primary caregivers of children with autism spectrum disorder within a South African context: venturing forward

<u>Dr Debbie Fewster</u><sup>1</sup>, Assoc Prof Kitty Uys2, Prof Pragashnie Govender<sup>1</sup>

<sup>1</sup>University of KwaZulu-Natal, Durban, South Africa, <sup>2</sup>University of Pretoria, Pretoria, South Africa

BIOGRAPHY: Debbie Fewster joined the University of Kwa-Zulu Natal Occupational Therapy team in 2013 after 18 years in clinical practice including psychiatry, pediatrics and neuro rehabilitation. She completed her MPhil in Group Therapy in 2014 with a special interest in autism and caregivers. She has published in the South African Family Practice Journal, SAJOT, Journal of Child & Adolescent Mental Health and co-authored a chapter in Occupational Therapies without Borders, 2nd Edition. Debbie has presented locally and internationally on her research. She was the recipient of an INSAR/Autism Speaks Emerging Researchers' Award in 2017 which has allowed her to collaborate with other researchers in Africa. In 2021/2022 Debbie was a team member of a development group developing a package of rehabilitation for individuals with ASD as part of a World Health Organisation initiative. Debbie has recently obtained her PhD in health sciences – occupational therapy. Alongside her research interests, Debbie has a passion for teaching occupational therapy and mentoring students, both undergraduate and postgraduate to reach their full potential. Debbie is a mom of two very busy boys and really has a heart to see parents thrive (not just survive!) in their roles as caregivers.

**Background:** Primary caregivers (PCGs) of autistic children (AC) play a pivotal role in their children's care. Caregiving may be stressful, placing PCGs at risk of mental health (MH) challenges and compromised quality of life (QOL). This study aimed to develop a contextually appropriate QOL practice model (QOLPM) for PCGs of AC in a South African context.

**Methodology:** A pragmatic approach was undertaken to develop a proposed model according to content, structure and mechanism of delivery (MOD). Model development, QOL and care co-ordination frameworks were included for construction of the model. A concurrent mixed methods design including three phases was adopted: item generation, evaluating known and new information about QOL interventions and exploring the perspectives of PCGs in their understanding of QOL and their care needs. Data collected at each phase of the study were analysed deductively using QOL and care co-ordination frameworks. Data were merged, analysed and interpreted resulting in the proposed model.

**Findings**: Content in phase one and two: awareness/education on ASD, interventions for the AC and interventions for the PCG. Content from phase three: education, support, skills training, parenting and self-management strategies as well as insights towards specific improvements in each domain of QOL. Structure and MOD was context driven with commonalities in approaches, specialisation and presentation. The QOLPM has its foundations in an asset-based approach. PCGs and related systems can facilitate improved QOL and reduce the burden of care. Practical guidelines for content, structure and MOD are within this asset-based approach.

**Conclusion:** The QOLPM embeds PCGs in a broader context of family, community and society who are potential assets that can foster improved QOL for PCGs. Autism has been a "trendy" topic with increased autism research. Will this proposed model be a catalyst to draw us together to affect change for AC and their PCGs?

### My Journey from a autistic adult to Postdoctoral Fellow

#### Dr Emile Gouws<sup>1</sup>

<sup>1</sup>University of South Africa (UNISA), Pretoria, South Africa

BIOGRAPHY: Dr. Emile Gouws is a Postdoctoral Fellow at the University of Johannesburg (UNISA) and an internationally renowned disability activist that attends Commonwealth and United Nations higher political meetings. Dr Gouws has recently been elected as the president of the Board of ICDL and is only the 3rd person to hold this position. In his free time, Dr Gouws was recently the Vice-chairman of the National Executive committee of Autism South Africa and currently represents underrepresented groups on the Commonwealth Disabled Peoples Forum, In 2023, Dr Gouws have been nominated for the Commonwealth Youth awards and is the first and only elected as a member of Africa from the Autistic research Committee of INSAR (International Society for Autistic research). Dr Gouws has contributed towards a variety of international articles and research papers on neurodiversity including a published article in Forbes magazine Japan. He is married to a beautiful Alexic autistic lady named Sammi who is also a autism self-advocate. Together they do advocacy on relationships and being married as an autistic couple

"My presentation will center on the nuanced development of my identity as an autistic adult, Ph.D. candidate, spouse, and advocate for autism self-awareness. The crux of this discourse will underscore the paramount importance of cultivating a robust support ecosystem—one that is both continuous and consistent. This framework is not only instrumental in fortifying my personal journey but also serves as a pivotal model for parents, encouraging them to establish analogous ecosystems with professionals such as psychologists and educators. Throughout the presentation, I will provide an insider's perspective to elucidate the intricate dynamics of navigating these roles and advocate for the imperative nature of fostering an inclusive and supportive community."

### Mental health of parents of children with developmental disabilities in Limpopo Province, South Africa

#### Prof Saraswathie Govender<sup>1</sup>

<sup>1</sup>University of Limpopo, Mankweng, South Africa

**BIOGRAPHY:** Professor Saraswathie Govender has a PHD in Psychology and is a C3 rated NRF researcher and serves as the Chairperson of the School Research and Ethics Committee and a member of the Faculty Higher Degrees Committees. Prof Govender's research interests are:

Gender and sexuality; Sport and performance; Health Psychology; Neuropsychology; Community based research and research into the developmental disorders. She has presenting papers several papers locally and internationally. She works closely with colleagues and students in the Department of Psychology (at the University of Limpopo) on several national and international funded research projects and has successfully produced several Masters and PhD graduates.

There is considerable evidence in the literature that parents of children who have a developmental disability experience an increased risk of mental health problems. The mental health risks of these parents are often under recognised, compounding family stress and entailing long-term consequences for well-being of the whole family. The current research aimed to determine the psychological sequelae in parents of children with developmental disabilities.

Using a quantitative quasi-experimental design it compared the psychological experience of parents with, and without, a developmental disorder by using three independent psychological scales of measurement i.e., The Family Environmental Scale (FES); the Perceived Stress Scale and the Symptom Checklist-90 Revised (SCL-9-R). The participants consisted of 42 parents of children with a developmental disorder between the ages of one to fifteen years and 43 parents with children who do not have a developmental disorder in Limpopo Province.

The findings indicated that elements such as cohesion (p < 0.000), expressiveness (p < 0.000) are lower in families who have a child with a developmental disorder, while the amount of conflict (p < 0.000) is higher on the FES. Also there is a lower expectation for achievement (p < 0.000), whilst less participation in intellectual, cultural, recreational and religious activities (p < 0.000) is prevalent. It was found that parents of children with developmental disorders exhibit, far greater levels of stress (p < 0.000) on PPS as well as elevated psychological symptom status on the (SCL-9-R) in the form of anxiety (p < 0.000); depression (p < 0.000) and hostility/anger (p < 0.000)) as compared to parents who do not have a child with a developmental disorder. Thus, the findings are in line with previous studies that caring for a child with developmental disorders is associated with an increased risk of psychological distress and family dysfunction.

### An investigation of alcohol and drug use and possible risk factors amongst nursing students at a University in the Western Cape

**Dr Gaotswake Patience Kovane**<sup>1</sup>, Professor Pat Mayers<sup>2</sup>

<sup>1</sup>North-West University, Mafikeng, South Africa, <sup>2</sup>University of the Western Cape, Mafikeng, South Africa

BIOGRAPHY: Dr Gaotswake Patience Kovane, Senior lecture at North-West University,

Qualifications:

- 1. Baccalaureus curationis with Summa Cum-laude
- 2. Masters in Advance Psychiatric Nursing,
- 3. Masters in Nursing Science-Research only
- 4. PhD Nursing Science

Award and distinction:

- 1. Summa Cumlaude BCUR
- 2. Nursing student award as best academic achiever (UWC)
- 3. Faculty of Health Science Award, best academic achiever

Focus Area

- 1. Psychiatric Nursing
- 2. Perinatal Mental Health

This study aims to investigate alcohol and drug use and possible risk factors amongst undergraduate nursing students at a university in the Western Cape Province, South Africa

A quantitative, descriptive survey design was utilised. Participants were recruited using a convenience sampling approach. A structured self-reporting online questionnaire was used and captured on a Research Electronic Data Capture (RedCap) database. Data were analysed using the SPSS version 27 statistical package for Windows. The statistical significance for all tests was set at a 5% and a 95% Confidence Interval, followed by bivariate results, Chi-square tests and multivariate regression.

212 questionnaires were completed, 81% (n=171) were females, and 19% (n=40) were males. One respondent did not indicate their gender. The most used substances by nursing students were tobacco (24.1%), alcohol (64.6%), and marijuana (23.7%). Few students had used 'hard' drugs such as cocaine. Alcohol and drug usage was higher among females than males in the 12 months preceding the survey. Significant associations between risk for alcohol and drug use were found on the following variables: gender, with females more likely to consume alcohol and drugs over 12 months; peer pressure was related to substance use.

Higher education institutions with health sciences students, including nursing students, should collaborate to develop guidelines for awareness of substance use, monitoring and support for students to limit alcohol and drug use and possible risk factors amongst undergraduate nursing students.

Research limitations/implications- limitation of this study was that the researcher selected the population sample by convenient sampling and among university in the Western Cape among nursing students and may be generalisable to similar nursing education institutions. As a self-reported survey, this relies on the respondents' honesty.

The study recommends education around early identification of substance use or risk factors that may lead nursing students to substance use.

### Towards an understanding of success of psychiatric nurses in caring for children with mental health problems: Appreciative Inquiry

Mrs Rorisang Machailo<sup>1</sup>, Prof Daleen Koen, Dr Molekodi Matsipane <sup>1</sup>North-West University, Mahikeng, South Africa

**BIOGRAPHY:** I am a lecturer and a PHD candidate at NWU. I am a psychiatric nurse specialist with more than 20 yeas clinical experience. I am currently an upcoming researcher in Psychiatric and mental health nursing with special interest in child and adolescent psychiatry

**Introduction:** Psychiatric nurses have a specialized body of knowledge and skills that is essential to provide care to persons with mental health challenges. Literature provides little evidence on child psychiatric nursing practice.

**Purpose:** The purpose of this paper was to explore the successes of the psychiatric nurses in caring for children with mental health problems using appreciative inquiry (AI).

**Design**: A qualitative explorative and descriptive design was used to allow for new ideas to change that can fundamentally reshape positively the practice of child psychiatric nursing. Appreciative Inquiry was used to collect data. Purposive sampling was used to select psychiatric nurses caring for children with mental health problems. Focus groups were used to collect data.

**Findings:** The results revealed both positive and negative realities of psychiatric nursing practice. The positive realities included commitment, passion and dedication of staff members beyond expectations to the children. The negative realities that needed urgent attention included lack of specific, integrated child mental health within the mental health care services, shortage of resources including material and staff and not fit for purpose infrastructure.

**Conclusion:** Appreciative inquiry demonstrated commitment of psychiatric nurses in caring for children with mental health problems and the potential for dedicated child psychiatric institution in realizing the needs of children.

Implications for practice: Children's needs must be met through a positive lens. It is worth using these positives in the health care system to address their needs. However, nursing values are core in meeting these needs. Psychiatric nurses must strive to be of value to the children. Understanding child psychiatric nursing practice through problem-based approach may not be helpful.

# Building an understanding to construct a plan: Occupational Therapy services provided to preschool aged children diagnosed with autism spectrum disorder across the different levels of service in Cape Town

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**BIOGRAPHY:** Tasneem Mohomed, a senior clinical educator at UCT. She has her master's degree in occupational therapy (MSc OT) and over 20 years' experience in the occupational therapy practice domain of child learning and development. Over the years she has gained clinical experience in working with children across various ages with developmental and neurological disorders. She has been working at UCT as a clinical educator since 2008 and developed a keen interest in child psychiatry and ASD through supervising final year OT students which led to her master's thesis.

Children with Autism Spectrum Disorder (ASD) experience difficulties with engagement in their occupations. Pre-school children with ASD living in South Africa are a particularly vulnerable population due to limited support for their needs from the public sectors of education and social development. Occupational therapists working in the public sector of health are well positioned to address these occupational engagement concerns, therefore the purpose of this preliminary study was to gain an understanding of the types of occupational therapy interventions as well as the rationale for the interventions provided to preschool children with ASD across different levels of the public health sector.

This study used a multi-phase, sequential, exploratory mixed methods research design to explore and describe the assessment and intervention approaches adopted to guide occupational therapy practice across the different levels of service. With occupational therapists being positioned to facilitate the occupational engagement of children with ASD it was important to gain a more in depth understanding using both quantitative as well as qualitative data analysis.

The preliminary findings of phase one, in which 92 files were reviewed across a total of four sites where the analysis revealed similarities in the ASD population seen, and the practice patterns of the six, female participants working in these sites. In phase two of the study two themes generated revealed that while working with children with ASD formed only part of their overall caseload, all six participants worked within the constraints of their work context to build an understanding of each child's occupational needs using a child driven approach. The second theme, constructing a plan together, described the value participants placed on collaborating with caregivers to both understand and address the impact of contextual factors on the engagement of the children.

The poster aims to generate discussion on the interventions being provided.

### Engaging with young people with mental health lived experience to inform the statistical analysis of a large South African dataset

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**BIOGRAPHY:** Ms Audrey Moyo is a first-year PhD student in Epidemiology at the University of Stellenbosch. Her PhD work focuses on applying statistical and machine learning methods to understand the relationship between mental health and cardiovascular health among young adults in South Africa. She is currently developing a research proposal for her PhD.

Audrey is also serving as a co-principal investigator for a South African Medical Research Council (SAMRC) study focused on mental health among young people aged 14-24. She works alongside her supervisor, Dr Darshini Govindasamy from SAMRC, and the team from Stellenbosch University. Together, they were the only team in South Africa to be awarded the Wellcome Mental Health Data Prize 2022 to conduct this study.

Additionally, Audrey holds an MPhil in Demography from the University of Cape Town. For her master's degree, she conducted research on the determinants of contraceptive use among young women. She also possesses a Bachelor Honours Degree in Applied Mathematics from the National University of Science and Technology in Zimbabwe.

**Background:** Mental disorders affect approximately 20% of young people annually globally. This study aimed to explore young people's lived experience of mental health, to inform the statistical analysis of a large South African dataset.

**Methods:** Group discussions were conducted with individuals aged 18-30 years in eThekwini municipality, KwaZulu-Natal province on 13 October 2022. Participants were invited from clinics, youth mental health NGOs, and youth enrolled in current studies. Seventeen participants (9 females and 8 males) receiving professional healthcare for mental health symptoms or overcame symptoms in the past year attended the session and all signed confidentiality agreements. Trained fieldworkers facilitated discussions in English and isiZulu. Topics included perceptions good life, factors contributing to mental health challenges, treatment access barriers, and coping mechanisms.

**Findings:** Views of a good life included mental health, social connections, physical health, education, and employment. Factors contributing to poor mental health included educational poverty, COVID-19 pandemic, single-parent households, food insecurity, unemployment, and flooding. Barriers to seeking mental health treatment included fear of judgement, financial constraints, lack of information and support, cultural norms, and trust and confidentiality issues. Coping mechanisms varied from negative behaviours like substance use and isolation to positive strategies such as physical activity, therapy, and social connections. Additionally, one participant remarked, "... the things we watch; the music we listen to influences us to want to become like that person on TV and do not get to be the person whom we are supposed to be which is part of the reason one finds themselves depressed."

**Conclusions:** Socio-economic, cultural, and environmental factors significantly influence young people's mental health. Recommendations include statistical analysis incorporating multi-level assessments of correlates and development of community-, school-, and tertiary institutional-based mental health educational programmes. Mobile-health initiatives to track and support young people experiencing mental health challenges are equally important.

### Mental health challenges faced by LGBT youth in Limpopo: a human rights and queer feminist intervention.

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**BIOGRAPHY:** Samukezi Mrubula-Ngwenya is a social justice activist who advocates for Lesbian, Bisexual and Queer (LBQ) rights in South Africa. She has a PhD in Political Science, University of Limpopo, where she lectures and convenes the Gender Studies Program. A former Fulbright scholar, Samukezi also holds a Masters in Women and Gender Studies, from San Francisco State University, US. Her research focuses on LBQ narratives and experiences, social movements, democracy and political activism, African sexuality and gender diversity. She is a member of South Africa's Presidential GBV, Summit 2 Planning Committee, and a technical committee member for Gender Desk, University of Limpopo which was officially launched in 2022. Further, Samukezi is the chairperson of a non-governmental organisation that advocates for sexual rights, and sexuality freedom Capricorn Ignited LGBTI in Limpopo.

Despite being the first African country to afford freedoms and constitutional protection to its gender non-conforming citizens, South Africa remains number one in terms of high rates of violence and hate crime murders against black gays, lesbians and transgendered persons. Queer youth, who form part of a population often described as the 'future of the country' are severely underserviced and neglected, and their holistic and psychological well-being is certainly sidelined due to immense inequality experienced in socio-political and socio-economic contexts. (Nyeck &Shepherd, 2022). There is a lot of discrimination and violence against LGBTQI+ people in the country. Moagi et al (2021) are also of the view that mental health challenges faced by the LGBTQI+ community stem from social and legal barriers faced by LGBTQI+ persons. These challenges include discrimination, victimisation and barriers to accessing healthcare services. While it is easier to access mental health support in major cities like Johannesburg and Cape Town, it is more difficult in rural areas due to a lack of available services, education on queerness and access to information. Using human rights and queer feminist intervention approach this study seeks to awaken the public, and raise awareness around the challenges and needs of queer, transgender and gender-diverse youth in Limpopo province, South Africa, related to mental health that is far too often stigmatised and neglected in an overburdened health sector. Findings reveal that heteronormativity is still accepted and normalised which in turn further perpetuates stigma and discrimination. Secondly, there is a need for workshops and programs on gender and sexuality and their intersection with mental health in rural areas in Limpopo.

## "We are on our own" - Caregiver perspectives of services for children with autism in rural and peri-urban areas in the Western Cape Province of South Africa

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**BIOGRAPHY:** Dr Sarosha Pillay is a lecturer at the Division of Occupational Therapy at the University of Cape Town where she is the head of the Child, Learning, Development and Play (CLDP) cluster. Her research interest is in education systems for children with autism in South Africa. She is a member of the Autism South Africa National Executive Committee.

**Background:** Caregivers of children with autism experience high levels of stress in accessing services for their children. Much of the research on autism comes from high income countries around the world. Current studies on autism in low- and middle-income countries (LMIC) focus mostly on urban services. There is little information on how rural and peri-urban caregivers experience having a child with autism and what services are available to them.

**Aim:** The aim of this study was to describe caregiver perspectives on the nature and extent of service needs for rural and periurban children with autism in the Western Cape province of South Africa and their suggestions for future service delivery.

**Methods:** A pragmatic qualitative research methodology was used. Semi-structured interviews were conducted with five caregivers of children who have been diagnosed with autism and live in rural and peri-urban communities across the Western Cape.

**Findings:** The main theme that emerged was "We are on our own". Caregivers felt that services for their children were significantly lacking. Their perspectives were captured under three categories. The first category described the challenges associated with caring for a child with autism while living in a rural or peri-urban area. The second category described the physical and human resource constraints inherent to living in a rural or peri-urban area and the third category described caregiver suggestions for improved services for their children.

**Conclusion:** Rural and peri-urban caregivers expressed dissatisfaction with current educational and other services for their children. They suggested educator training, curriculum differentiation, caregiver training and respite as ways to improve services and reduce the burden of caring for a child with autism in a rural or peri-urban setting.

### Understanding and supporting families with TSC-Associated Neuropsychiatric Disorders (TAND) in India – study proposal

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**BIOGRAPHY:** Ms. Shoba Srivastava is a parent of a young man with Tuberous Sclerosis and autism. She is one of founder trustees of SOPAN. She has a degree in Special Education with a post graduate degree in education. She has worked with children with autism and other disabilities. As a parent, her experiences with working with her child have helped her working with other children with autism.

Ms. Srivastava has contributed significantly towards expansion of SOPAN's projects and broadening its horizons. She has worked towards setting up each project and thereafter ensuring its smooth functioning. She has worked towards creating fund raising opportunities for SOPAN. She has forged relations with many institutions and groups who provide a platform for showcasing skills of individuals with autism and developmental disabilities through exhibitions of products. She has been instrumental in organizing community awareness programs aimed at sensitizing the general public and in garnering their participation in SOPAN's projects.

Shoba Srivastava is a guest lecturer at Suvidya College of Special Education (A project of SOPAN) which conducts the B.Ed in Special Education (Autism) and is affiliated to University of Mumbai and recognized by Rehabilitation Council of India. She has delivered lectures on autism and disability specific teaching strategies and methodologies at other institutes as part of their curriculum

Shoba Srivastava was a member of Institutional Review Board (IRB) of Kasturba Hospital, Mumbai since 2013. As part of the IRB she has reviewed several research papers which have come to the IRB for approval.

Shoba Srivastava is a member of Tuberous Sclerosis Alliance of India (TSAI). She has worked towards creating a network of families in India and has facilitated in organizing meetings and workshops of TSAI in India. She is currently pursuing her Ph.D. at the University of Cape Town.

**Introduction:** Tuberous sclerosis complex (TSC) is characterized by benign tumors in the body, drug-resistant epilepsy, and a wide range of difficulties, referred to as TSC-associated neuropsychiatric disorders (TAND). A recent scoping review found very little TAND-related research in India. This project aims to understand and address knowledge gaps in India. An international group of researchers, clinicians and family experts recently set up a research project 'TANDem' and developed a TAND-SQ Checklist to track TAND profiles. The checklist was built into a smartphone application that links profiles with a toolkit consisting of resources for the TSC community. This tool has potential to address the knowledge gaps in TAND in India. Quality of life of caregivers of individuals with TSC is significant. The study aims to provide support through web-based training modules.

#### Aims:

- Explore the perspectives of Indian families and professionals regarding TAND.
- Evaluate feasibility and acceptability of the TAND-SQ Checklist and the TAND app in India
- Evaluate the feasibility, acceptability, and efficacy of web-based caregiver wellbeing programme in India.

#### Methods:

Aim 1: Qualitative analysis of data obtained from focus group discussions (FGDs) with families and semi-structured individual interviews with professionals.

Aim 2: 50 families will complete the TAND-SQ and browse through the TAND app. Mixed methods will be used to analyse quantitative feedback via a feedback form, and qualitative feedback via FGDs with a subset of families.

Aim 3: A 3-session web-based caregiver wellbeing programme will be administered to 16 families. Mixed-methods will be used to evaluate the programme through feedback forms and FGDs

#### Conclusions:

The study may lead to improved understanding of the needs of TSC community in India and may lead to potential scale-up of the tools and interventions used in the study in India.

### Mental Health Digital Innovations Ethical Concerns among Young People In Kenya

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**BIOGRAPHY**: Sarah is a psychiatrist trained at the University of Nairobi, Kenya. She has worked as a psychiatrist at level 5 and level 6 hospitals in Kenya after her qualification, and developed an interest in Child and Adolescent Psychiatry. She is currently a member of faculty at the Aga Khan University, Nairobi and begun her fellowship in Child and Adolescent Psychiatry at the University of Cape Town in February 2024.

The ethics for mental health digital innovations for young people (EMDIYA) was developed by group of expert academic advisors, consultants, early career researchers and young people in 5 African countries: Kenya, Uganda, Zimbabwe, Ghana and South Africa. Its activities included mentorship, capacity building and engagement of young people. Increased use of information technology across Africa has led to use of digital innovations by young people to increase access to mental healthcare. Their use especially increased during the COVID 19 pandemic. In 2020- 2021, the Kenyan team engaged stakeholders and youth leaders with an aim of developing a framework for responsible and relevant mental health innovations. The specific objectives were to identify the risks, benefits, facilitators and barriers associated with digital mental health innovations among the youth. Data was collected via Focused Group Discussions (Youth leaders) and Key Informant Interviews (stakeholders). The results found that the mental health needs of the youth are neglected leading to a huge gap in care and they have embraced digital innovations to bridge this gap. Many innovations addressing mental health were identified, but they are not regulated by any professional body. Majority were not developed or being run by mental health professionals. Ethical issues identified included lack of confidentiality and privacy. The absence of these ethical principles and guidelines could potentially lead to more harm than be benefit to the users. The advantages of the innovations were affordability, accessibility, acceptability and adoptability. Youth from rural areas and lower socio-economic backgrounds were however identified as being disadvantaged due to poor access to the digital innovations. Recommendations from the study highlighted the need for research governance on digital mental health innovations, professional governance on provision of digital mental health services, and development of a youth led network and advocacy platforms focusing on youth mental health.