

Improving sex, rights and relationships education for students with intellectual disability and on the autism spectrum: Importance of co-production

PROFESSOR IVA STRNADOVÁ



Overview



- Co-producing knowledge in inclusive research
- The latest research on sex education for students with intellectual disabilities and on the autism spectrum
- Experiences of students and teachers at NSW schools
- Rights and Relationships Program

The Research Program Team



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The Process of Deinstitutionalization... ...Becoming a Fellow Traveler of People with Intellectual Disabilities



Combining Research with Advocacy

Self Advocacy Sydney



NSW chapter of Australian Association of Special Education



“Co-production has an important role to play in rethinking and remaking the world for the better... it offers possibilities to academics and communities interested in working together to further the aims of social justice.”

Co-producing Knowledge in Inclusive Research

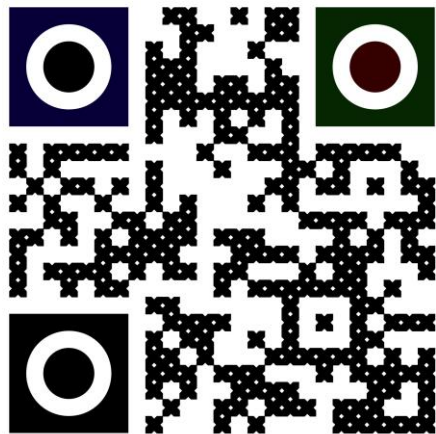
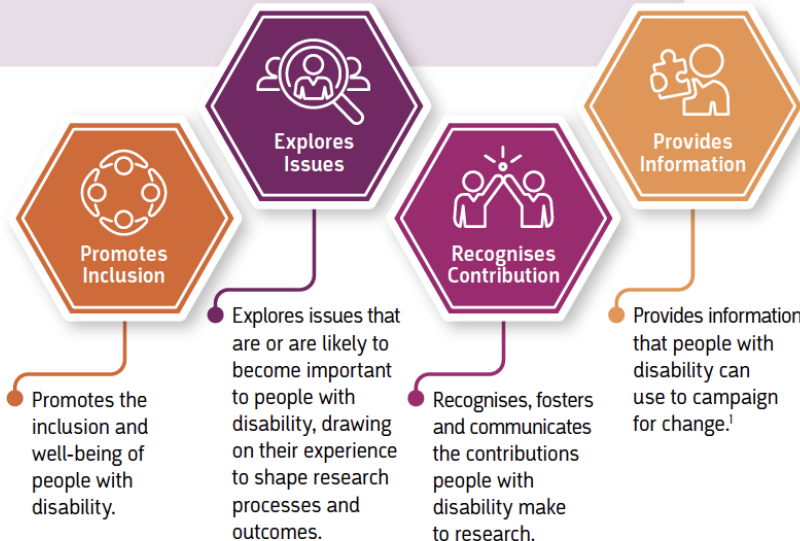
DOING RESEARCH INCLUSIVELY:

Guidelines for Co-Producing Research
with People with Disability



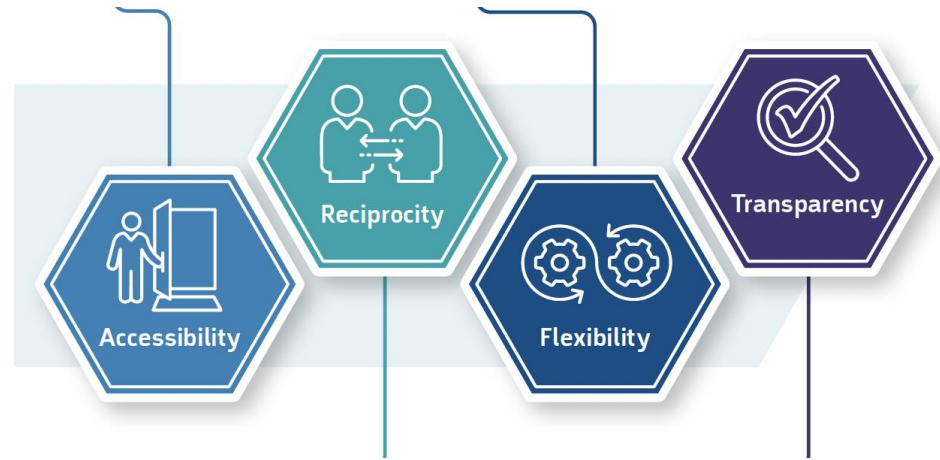
DOING RESEARCH INCLUSIVELY:

Co-Production in Action



SCAN ME

Principles of Co-production



Inclusive Research

= Research in which people with intellectual disabilities are included in the role of researcher



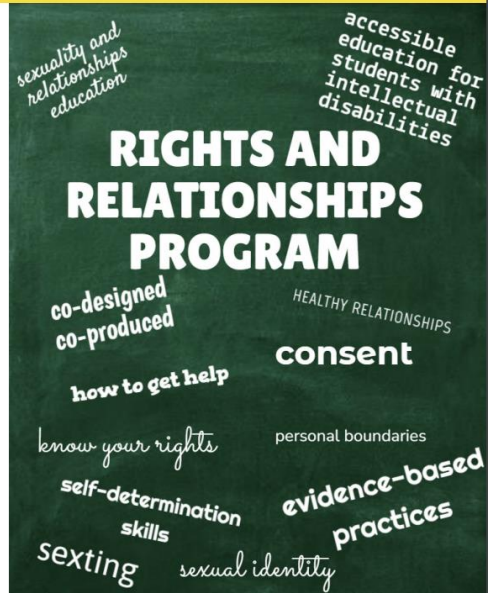
GeneEQUAL is a research program to help people with intellectual disability get better health care



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**Sex education in schools: Building
an evidence base for programs with
students with intellectual disability**

Iva Strnadová, Julie
Loblinzk, Joanne Danker,
Allison Carter, Benjamin
Garcia-Lee, Sarah Hayes,
and Caroline Basckin



This presentation will discuss themes that may be triggering for some people.

If at any time you need to take a break, please do so.

If you wish to speak to someone after this presentation, please contact Iva



TRIGGER WARNING

Themes that will be discussed:

- Sexual violence
- Abuse

Many people with intellectual disabilities experience



- Bullying
- Sexual abuse
- Physical abuse
- Financial abuse

What Research Tells Us

Women with intellectual disabilities have higher rates of:

- All forms of abuse and violence
- Unwanted and unplanned pregnancies
- 40-60% child removal
- Sterilisation – without consent
- Long-acting contraception – without consent



Katarina said

So, when I hit puberty, I was still playing with my dolls. (...) I was raped at 14, ended up having a baby at 15...

Sammy said

I get transport money (...) and my dad feels that he has the right to it. (...) That's for me. I only get \$68 from NDIS for transport. My dad's charging me \$70.

What people with intellectual disabilities say

They are:

- Sexually active and interested in having sexual relationships
- 84% already have had sexual relationships



Aware that they received less information
than their 'mainstream' peers

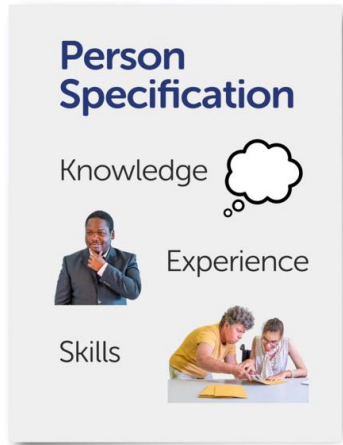
What people with intellectual disabilities say

They want:

- Same desires for sexual relationships as ‘mainstream’ peers
- Intimate relationships
- Have children and get married
- Opportunities to discuss sex and have “girl talk/girl space”
- To learn more, be better informed



Sex Education is Critical for a Successful Transition to Post-school Life



- Enables students to develop knowledge and skills
- Resources students to make informed choices regarding their sexuality and relationships
- Supports self-determination and counteracts overreliance on adults

Research on Sex Education



- People with intellectual disabilities receive less sex education than their peers
- Deficiencies in sex education for adolescents with intellectual disabilities
- This leaves students ill-equipped to identify warning signs of sexual abuse and exploitation

Scoping Review on Sex Education



- 18 studies published from 2011 to 2019
 - Students' perspectives (n=8)
 - Parents' perspectives (n=6)
 - Teachers' perspectives (n=4)
- Conducted in 9 countries (e.g., USA, UK, Australia, South Africa)

Strnadová et al. (2022)

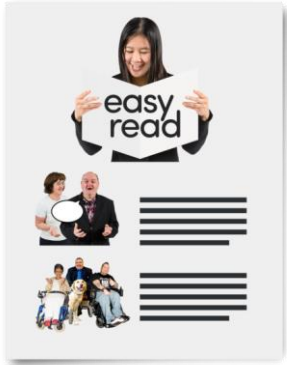
Findings from Scoping Review

- Fewer formal opportunities for sex education
- Teachers and parents have positive attitudes but also act as gatekeepers to sex education
- **Barriers:**
 - Teachers' beliefs and misconceptions about students with intellectual disabilities
 - Inappropriate delivery of sex education,
 - Lack of knowledge about evidence-based practices



Findings from Scoping Review

- **Content taught:**
 - Staff attitudes and training curricula largely dictated what was “taught, how and when”
- **Facilitators:**
 - Whole-school approach
 - Use of person-centred and accessible resources



Relevant and Topical

Consent Education reform

- Holistic and earlier consent education

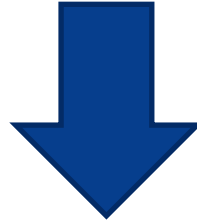


Consent Laws reform

- Proposed changes to consent Laws, were passed through the lower house on Wednesday 10th November 2021
- Changes are based around 'affirmative consent'

Research Aim

- What experiences do students with intellectual disabilities have of sex education?



- Interviews with:
 - students with intellectual disabilities (n=11)
 - their parents (n=9)
 - teachers (n=10)



Key Findings - Teachers



- **Majority of the teachers** had experiences with their **students with intellectual disabilities** being **sexually abused**
- Teachers also mentioned **incidents of domestic violence in families** of their students

Key Findings - Teachers



- **Only three teachers** stated that students with intellectual disabilities attend their IEP meetings
- Furthermore, **only two teachers** mentioned that parents receive a copy of an IEP
- **None of them** would say that students receive their copy

Key Findings - Students



1. Topics omitted or underexplored in sex education
2. Sex education inaccessible to students
3. Students are not included in Individual Learning Plan meetings
4. Students are not consulted about what they would like to learn in sex education

Omitted or Underexplored Topics



- Planning pregnancy
- Online dating
- Masturbation
- Sexual and gender identities
- Domestic violence



Sexual and Gender Identities

“I feel like they should have spent more time on identity, because my friend, who’s still in high school, my best friend, ... he’s transgender, and they don’t spend any time on stuff like that ...and I have a friend who has body dysmorphia ...but again, I didn’t know they have this, because, again, they don’t tell you anything at school about it. You had to find out through someone else, like, “Oh, if you’re feeling like this, maybe you have this.” They’re like, oh, my god, I feel so much better, knowing I have a name to this! It was like, yes, names help! ...It also makes you feel like, well, hey, if there’s a name for this, I’m not the only one who’s feeling it!”

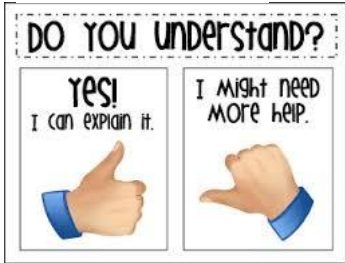
“I think, is the problem, that if I went up to a teacher and asked, “I heard this word ‘asexual’, what does it mean?” I have a feeling that most teachers would be like, “I have no idea. Go Google it.”

Recommendations



- Use plain/ Easy English resources
- Use videos, pictures
- Use repetition
- Use words that are not complicated
- Explain new terms
- Keep on checking for understanding

“I want to know, but I don’t understand the way you’re teaching.”



On Language

“...they talk in really complicated terms. Even though they say short, simple lines, they have really big, complicated words in the middle of them. And explaining what one word means, and you don’t explain what the second word means, then you’re like, “This means this, but what means this, and what does this mean?””

“During Year 8, when I had Miss X, I was actually interested some of the time, because she would explain the words to me, and it would be like, oh, I understand that! This actually sounds interesting, now that I know what it means. Let’s continue. I still wasn’t great at it, but at least I felt like I was understanding it.”

Implications for Schools



- Sex education needs to include all topics
- Sex education needs to be accessible
- Students need to be consulted what they want to learn
- Students need to be present and involved in Individual Learning Plans meetings
- Students need to receive an accessible copy of their Individual Learning Plan

“...Collaborative curriculum planning will determine the **most appropriate curriculum options** for students with **special education needs** in keeping with their **learning needs, strengths, goals and interests.**”



Most students with special education needs will **participate fully in learning experiences** based on the **regular syllabus outcomes and content...**”

Implications for (Inclusive) Education

Pre- and in-service teachers' training should:



- Highlight the importance of teaching in accessible way
- Incorporate lifespan perspectives
- Build on evidence- and research-based knowledge

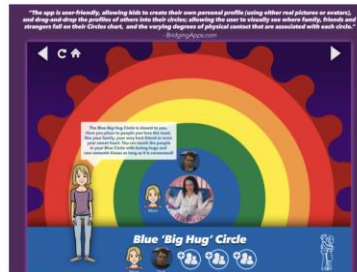
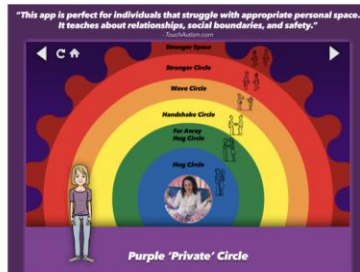
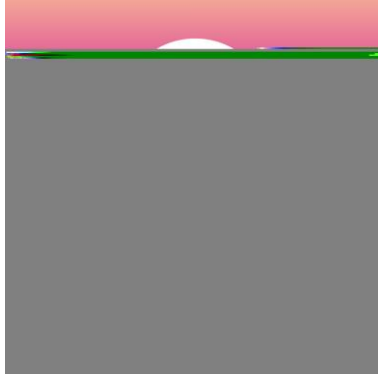
Evidence-Based Practices



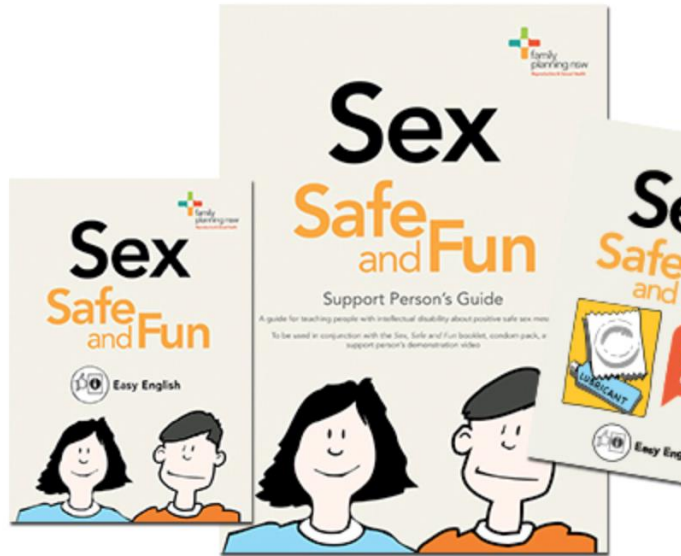
- Technology-Aided Instruction and Intervention
- Self-management instruction
- Video-modeling

Technology-Aided Instruction and Intervention

- Video prompts to learn dating skills
- Interactive computer software with avatar assistants to learn how to recognize abusive behaviour
- A smartphone app for girls/women who experienced abuse

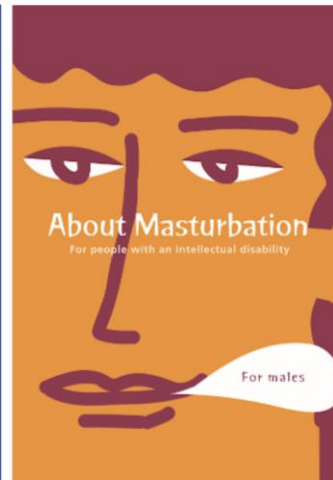
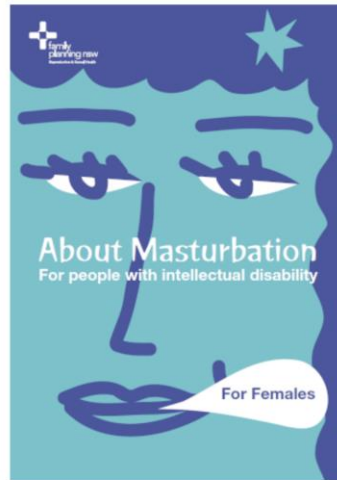


NSW Family Planning



About Masturbation

About Masturbation for People with Intellectual Disability- For Males and Females



BEING A HEALTHY WOMAN



An educational resource for women with intellectual disability, their families, health care providers, carers and support workers



NSW@HEALTH

SECCA



Free

The SECCA App

A free innovative resource to support relationships and sexuality education for people of all ages and abilities.

[Learn more →](#)



Free

Internet Safety Cards

Help to stay safe online

[Learn more →](#)



Free

Safe Sex Brochure

Information about STIs and safer sex, including how to use a condom.

[Learn more →](#)



\$995

Sexuality and Relationships Teaching Resource



Free

Sanitary Bin Notice



Free

Sexting Brochure



Sexual Lives & Respectful Relationships

125 likes • 130 followers

[Learn More](#)

[Message](#)

[Like](#)

Living Safer Sexual Lives: Respectful Relationships (Frawley, Slattery, Stokoe, Houghton, & O'Shea, 2011)

Co-producing Knowledge in Inclusive Research

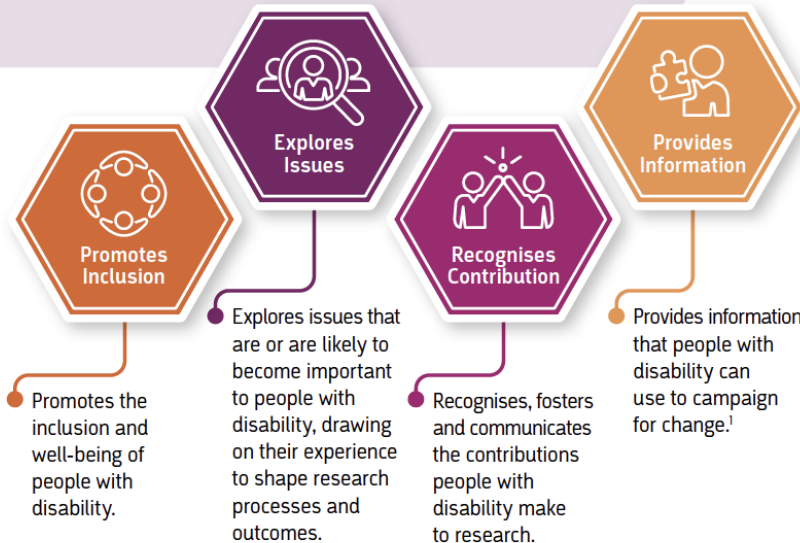
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DOING RESEARCH INCLUSIVELY:

Co-Production in Action



Rights and Relationships



This training is a face-to-face course to empower young people with a disability by learning about their rights in relationships

It consists of 4 sessions facilitated by the Ability Rights Centre Education Team

Topics include:

- Relationships and the law
- Healthy and unhealthy relationships
- Public and private boundaries
- Safe relationships and technology



For more information

contact the Ability Rights Centre on **02 9265 6350**
Jessica: jessica@idrs.org.au • Robyn: robyn@idrs.org.au



Rights and Relationships ILC
Grant is funded
Department of
Social Services



Ability Rights Centre

A SERVICE OF IDRS

Rights and Relationships Program (R+R)

- Relationships and the law
- Healthy and unhealthy relationships
- Public and private boundaries
- Safe relationships and technology

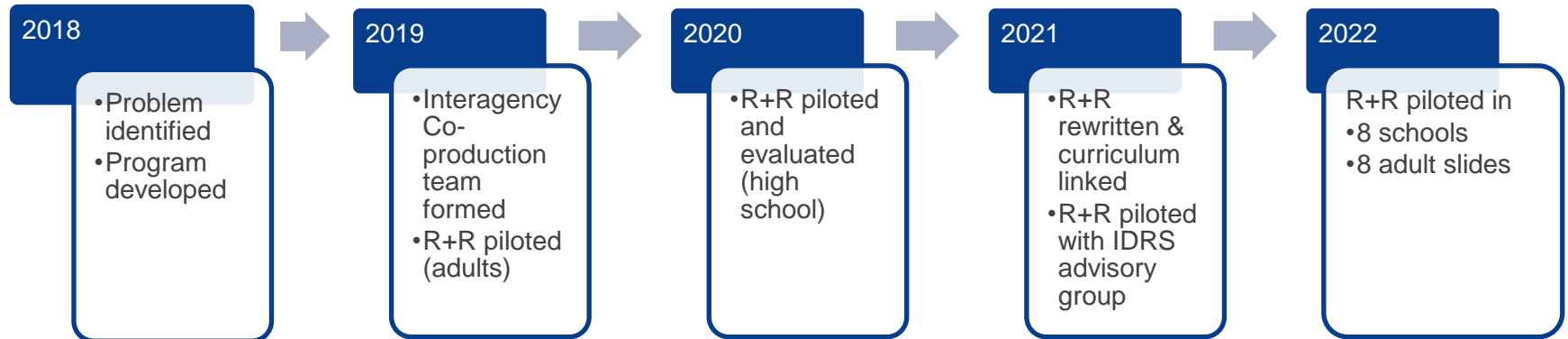
Rights and Relationships Program

R+R



- Program developed by the Intellectual Disability Rights Services (IDRS)
- Co-developed and co-delivered by educators with and without intellectual disability
- Piloted with adults with intellectual disabilities and with Year 12 students

Co-production in Action



Andre, Year 12 student with intellectual disabilities

Now I know if someone comes to me, like and they are talking about a problem at home, and it is like a domestic violence case and they don't know (because they haven't done the course), now I know, because like this list here it is all domestic violence. Like if they say, my husband is just constantly shouting, when he gets home. So, you are then much better at giving advice because you understand what consent is. Knowledge is power.

Matt, Year 12 student with intellectual disabilities

You can tell generation after generation the right information, because we have the right information and not dodgy information, like it fills the puzzle, not missing some of the parts of it.

Learning from the Piloting Process

Student: Ah, OK. It's like...it's kind of...they kept talking about Facebook, and then it's like...that's for old people.

Interviewer: Yeah. Right.

Student: It's like, who uses Facebook? Old people! It was like...that was like...

Interviewer: That's OK. That's a really good point. So, what would be a better focus than Facebook?

Student: People are pretty much past Facebook at this point. Instagram or Twitter...

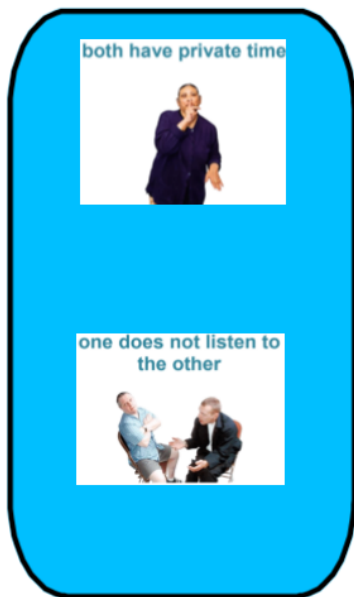


Healthy and Unhealthy Relationships

Everyone has a card.

Put your card where you think it should go.

Ask yourself: Is that an example of a healthy or unhealthy relationship?



Healthy Relationship	Unhealthy Relationship



What activity can you do in what space?

Put your activity card to match with a space.

lounge room



bedroom



have naked sex



get dressed



What is an AVO?



- Alex was given an AVO. Is he able to talk to Melanie? Or go to her house?
- What were the conditions of the AVO?
- Who could Alex speak to for help?



Example of Curriculum Link

Content/Learning Intentions/Key Questions	Teaching, learning and assessment	Resources
<p>PDLS-2: demonstrates help-seeking strategies and behaviours</p> <p>PDLS-3: use strategies to access health information and support services available in the community</p> <p>PSLS-4: uses appropriate strategies and behaviours to establish and maintain respectful relationships with others</p> <p>PSLS-10: develops skills for effective self-management</p> <p>PSLS-11: uses appropriate interpersonal skills to engage respectfully with others in a variety of contexts</p>	<p>Sexting and the Law</p> <p>The class will be shown short video clip/s. Students will discuss the content in the video clip/s and answer short summary question/s to clarify and reinforce the content. Students use their thumbs up, thumbs down paddle to answer a questions.</p> <p>Sexting and the Law</p> <p>Watch: Sexting and the Law Video</p> <ul style="list-style-type: none"> Can you send a sext to someone who does not want it? Can you share a sext with your friends that someone else has sent you? Is it against the law to share sexts with other people? <p>Watch: Sexting and the Law 2 Video</p> <ul style="list-style-type: none"> Can Jack have a sexy photo of Mia? Why can't Jack have a sexy photo of Mia on his phone? <p>Watch: Sexting and the Law 3 Video</p> <ul style="list-style-type: none"> Was it okay for Tom to share sexy photos of Amy with other people? Can you go to jail for sending a sexy photo of someone else? Should you keep a photo that someone else has shared with you on your phone? What should you do? <p>Watch: Sexting and the Law 4 Video</p> <ul style="list-style-type: none"> Can you put a sexy photo on social media? Is it against the law to threaten to share sexy photos? Can you a send a sexy photo to someone if you both consent to it? If you are worried or need more help what can you do? 	<p>Resources:</p> <ul style="list-style-type: none"> Thumbs up, thumbs down paddles <p>Videos:</p> <ul style="list-style-type: none"> Sexting and the Law 1 Sexting and the Law 2 Sexting and the Law 3 Sexting and the Law 4 <p>Smartboard Notebook Slide:</p> <ul style="list-style-type: none"> Sexting and the Law 1 Sexting and the Law 2 Sexting and the Law 3 Sexting and the Law 4

Value of Co-production

Chris, IDRS co-educator

Experiencing, like, what you've been through, and then telling a story, it can be really powerful to other people, and to some people, they've never experienced it, so they wouldn't know what it's like. So, it's tricky, but I think the experience that you had growing up or growing through that is important to actually tell your side of the story, as they say."



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