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

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Research Brief

What is the problem?

The UN Convention on the Rights of Persons with Disabilities acknowledges the rights of people with disability to “sexual health, safety in relationships and a full and meaningful social and intimate life.” UNESCO’s International Guidelines on Sexuality Education states that all youths including those with disability are entitled to sex education presented in an accessible way (UNESCO, 2018).

Research shows that the sex education students with intellectual disability receive is inadequate (Strnadová et al., 2021) and that this results in increased risk of:

- Being up to 4 times more likely to be sexually abused compared to typically developing peers (Barnard-Brak et al., 2014);
- Exploitation and abuse (Stein et al., 2018);
- Unintended pregnancy and sexually transmissible infections ([Carter et al., 2021](#));
- Further exclusion of these students due to the inability to fully exercise their self-determination skills and agency in regard to their sexual life (Rowe & Wright, 2017).

What is wrong with sex education for students with intellectual disability?

- Sexual health-related information is rarely available in accessible formats and topics made available are narrowly focused and limited in scope (McDaniels & Fleming, 2016);
- While contraception and safe sex tend to be the main topics taught at school; topics such as planning for parenting, gender identities, diverse sexualities, healthy relationships, and masturbation are frequently neglected (Strnadová et al., 2021);
- Programs are generally heteronormative and adopt a medical and biological view of sex and sexuality (Löfgren-Mårtenson, 2012).

The importance of sex education

Sex education is critical for a successful transition to post school life:

- It enables students to develop knowledge and skills (Swango-Wilson, 2011);
- Resources students to make informed choices regarding their sexuality and relationships (Phasha & Runo, 2017);
- Supports self-determination and counteracts over reliance on adults.

How we addressed the problem

Building on our recent reviews of the literature (Carter et al., 2021; Strnadová et al., 2021) and the priorities identified by students with intellectual disability, we developed a research program consisting of several research projects aiming to address this gap:

- Study of student's perceptions of and experiences with sex education (Strnadová et al., 2021);
- An evaluation of a sex education pilot program (Strnadová et al., 2020), and
- An evaluation of the initial rollout of a curriculum linked sex education program (in progress)

Study 1:

High school girls' perceptions and experiences of sex education

An inclusive study that explored high school girls with intellectual disability perceptions and experiences of sex education. The study also analysed how they envision their future in terms of relationships. A total of 11 Australian high school girls aged between 13-20 years with intellectual disability, 9 parents and 10 high school teachers participated.

Findings

The girls reported that contraception and safe sex were the main topics taught at school while planning for parenting, gender identities, diverse sexualities, healthy relationships, and masturbation were frequently neglected. This indicates that high school girls with intellectual disability do not receive a comprehensive sex education program. Omitting the topic on parenting is concerning as all but one girl in this study planned to have or foster children. Most girls with intellectual disability were also not included in Individual Learning Plan (ILP) meetings or consulted on the topics they wished to learn in sex education. This reduces the opportunities for students with intellectual disability to develop their sense of agency and self-determination skills, both of which are crucial for a successful transition to post-school life.

Excluding students with intellectual disability from ILP meetings also contradicts the 'collaborative curriculum planning process' that states that appropriate curriculum options and adjustments for students with disability must involve a team with significant **knowledge and** understanding of the student, which include the student themselves.

Students' preferences and needs should also be at heart of transition planning. The learning characteristics of students with intellectual disability were not fully accounted for in the delivery of sex education. While diverse resources were used, the language used to explain concepts remained inaccessible and limited students' understanding of the information presented. Consideration for teachers to simplify terms and provide visuals to better illustrate relevant vocabulary is needed.

Study 2:

Rights and Relationships: A curriculum linked sex education program

The research team conducted a research evaluation of the pilot of the Rights and Relationships program, developed by the Intellectual Disability Rights Service (IDRS). The program was piloted with nine Year 12 participants in the Disability Support unit at Matraville Sports High School, in Chiefly, NSW. The pilot was a collaboration between IDRS, Self Advocacy Sydney and UNSW.

The program teaches participants with intellectual disability:

- Practical strategies about how to recognise and respond to inappropriate behaviours and harmful situations;
- Builds their decision-making abilities and supports the development of healthy sexual identities; and
- Introduces and familiarizes students with appropriate supports (including legal) as required.

Findings

The evaluation of the Rights and Relationships Program indicated that it fills an identified gap in the curriculum and is an accessible program that is relevant and appropriate for high school students with intellectual disability. Specifically, the program had a positive impact on the students' knowledge and awareness in two key areas, Apprehended violence orders (AVOs) and consent.

Study 2:

Rights and Relationships: A curriculum linked sex education program

Study 2 has led to a further evaluation of the Rights and Relationships program being currently undertaken with 8 high schools (metropolitan and regional) and 8 adult disability services to assess its appropriateness and effectiveness for expansion to other NSW high schools and adult disability services. This evaluation uses a developmental evaluation approach which is focused on constant revision and enhancement of the program throughout all phases of the rollout and evaluation. This project is due for completion in 2023.

Key insights

- A comprehensive sex, rights and relationships education program for students and adults with intellectual disability must include a wide range of topics in accessible formats.
- Students should be consulted on the sex education topics that are of relevance and interest to them.
- Delivery of information in sex education programs should be inclusive and students' level of support needs must be considered.
- Individual Learning Plan meetings could provide the space to discuss students' preferred topics, and the level of support and adjustments needed in the delivery of sex education programs.
- Program collaborations between schools, NGO's and universities can support the development and implementation of relevant, effective and accessible sex education programs for students with intellectual disability.

About the Researchers



Iva Strnadová

Iva Strnadová, PhD, is a Professor in Special Education and Disability Studies at the University of New South Wales in Sydney, Australia. She is also Academic Lead Research at the Disability Innovation Institute at the UNSW. Her research aims to contribute to better understanding and the improvement of the life experiences of people with disabilities, especially people with intellectual disabilities. Combining research with advocacy is essential in her research program, which builds on supporting the self-determination (including self-advocacy) of people with intellectual disabilities, and is grounded in an innovative inclusive research approach.

Further details are available at [Disability and me blog](#), Disability and me Facebook page, and Twitter [@IvaStrnadova](#).



Joanne Danker

Joanne Danker, is a Lecturer in Special Education in the School of Education at the University of New South Wales. She specialises in the well-being of students with developmental disabilities (i.e., autism spectrum and intellectual disabilities), inclusive and special education, and enabling the voices of individuals with disabilities in research.

Further details of her work can be found at <https://research.unsw.edu.au/people/dr-joanne-cherie-danker>



Julie Loblinzk

Julie Loblinzk, is a Self-advocacy Coordinator at Self Advocacy Sydney, Inc. She is also an Adjunct Lecturer at the University of New South Wales in Sydney, Australia. In her role she lectures to undergraduate and postgraduate students about topics such as self-advocacy and parenting with intellectual disability. She is also involved in inclusive research and is currently working with Prof Iva Strnadová on numerous research studies.

Further details of her work can be found at [Disability and me blog](#) and Disability and me Facebook page.



Allison Carter

Dr Allison Carter, PHD, MPH, is a Senior Lecturer with the Kirby Institute, UNSW Sydney, an Associate of the Australian Human Rights Institute, and an Adjunct Professor at Simon Fraser University, Canada. Her research program aims to strengthen responses to gender, social justice, and sexual and reproductive health and rights, by and with communities. She has expertise in combining qualitative and quantitative methodologies with theory from the social sciences. She also specialises in critical approaches to community-based research, intersectionality theory and analyses, and creative methods of knowledge translation.

Further details of her work can be found at www.dralliecarter.com.

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Benjamin Garcia-Lee

Benjamin Garcia-Lee is a Scientia PhD scholar in the School of Education, UNSW. His research is focused on belonging in the lives of people with intellectual disabilities.



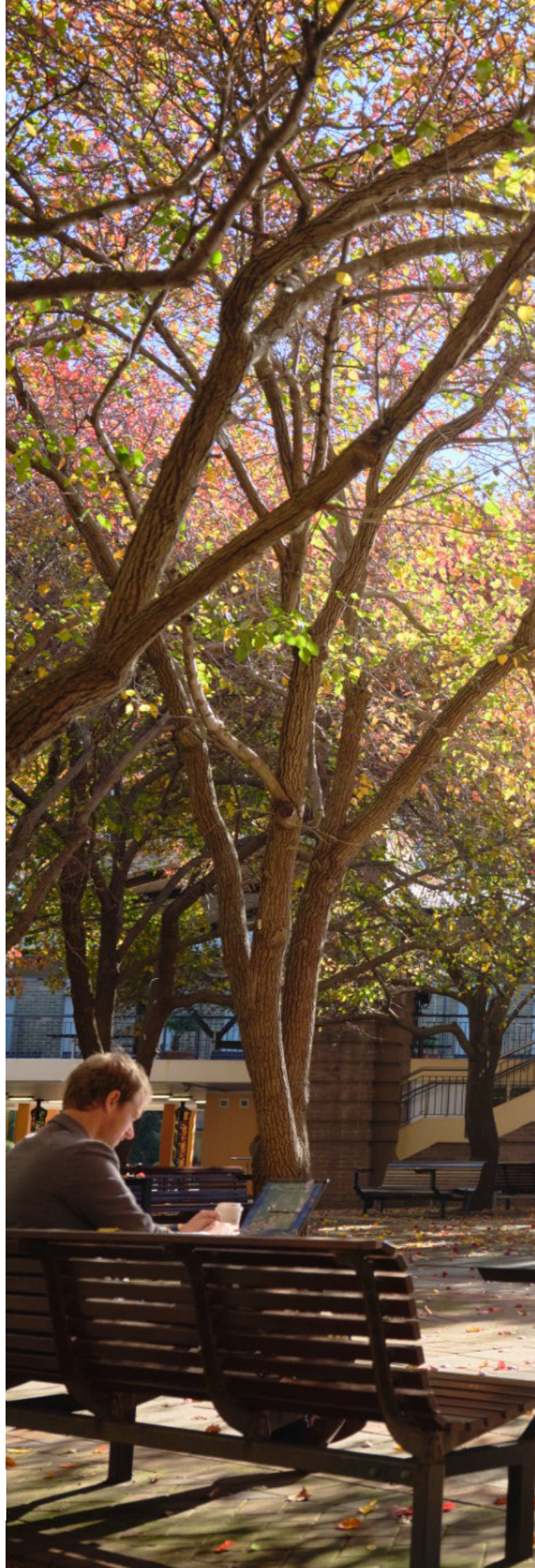
Sarah Hayes

Sarah Hayes is a Master of Education by Research student in the School of Education, UNSW. She is a primary school special needs education teacher and has experience working with students with intellectual disabilities in a school context. Sarah's research is focused on sexuality and relationship education for high school students in NSW.



Dr Caroline Basckin

Caroline Basckin is a casual academic in the School of Education, UNSW. Her research is focused on evidence-based practices to support students with disability and foster inclusion.





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For more information

Requests for further information and/or media enquiries can be directed to Prof Iva Strnadová for the Research Brief.

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Special and Inclusive Education Research Group

Research into special and inclusive education aims to understand and respond to the needs of students with a lived experience of disability. An associated research team at UNSW – the Special and Inclusive Education Research Group (SIERG) – seeks to engage with the wider community of schools, people with disability, and service providers with the goal of improving the outcomes of people with disability at all stages of education.

SIERG membership is comprised of prominent researchers, higher degree research students, educators, and people with lived experience of disability. Much of this research is accomplished through participatory and inclusive research, action research, and community consultation.