

Barriers, enablers and approaches to parental relationships and sexuality communication between parents and caregivers and children with Intellectual Disabilities and Autism Spectrum Disorder: A scoping review

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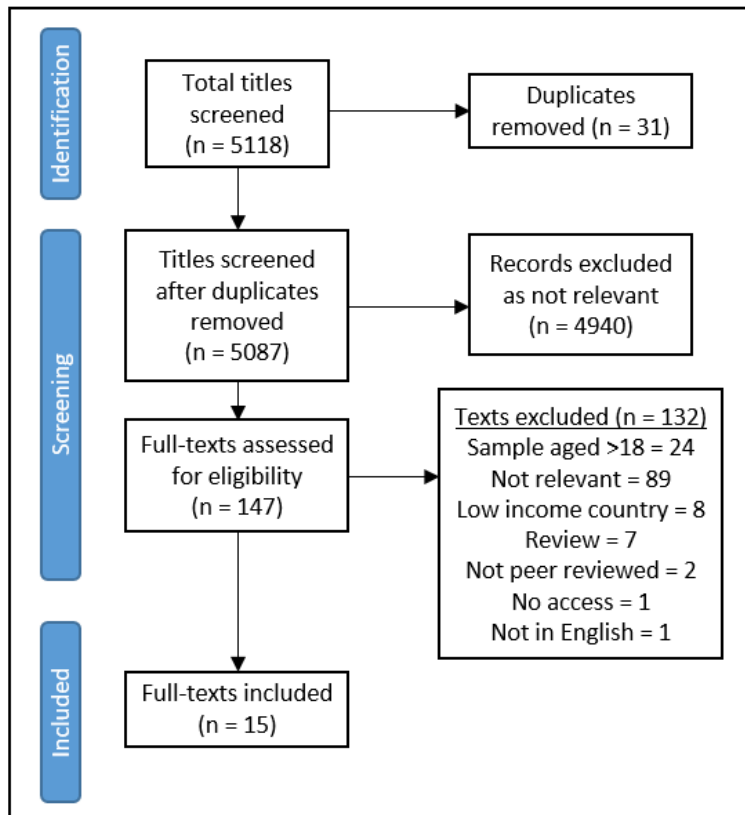


- Sexuality, intimacy and relationships are essential to humans' lives.
- WHO's ICD-10 classifies 11 'neurodevelopmental disorders' of which Intellectual Disability (ID) and Autism Spectrum Disorder (ASD) are two.
- ID-intellectual functioning and adaptive behaviour.
- ASD-challenges with social communication, sensory processing, and restrictive or repetitive patterns of behaviour, interests or activities.
- Distinct conditions-can co-occur

- Lack sexual interest or are asexual, many have had their sexuality 'infantilised' or denied.
- Describe their relationship experiences much the same way as those without ID
- Greater barriers to the expression of their romantic and sexual feelings than their typically developing peers:
 - They may be more socially isolated and lack the opportunities for sexual expression
 - Their sexuality may be viewed as problematic by family or society
 - They can lack access to the necessary information

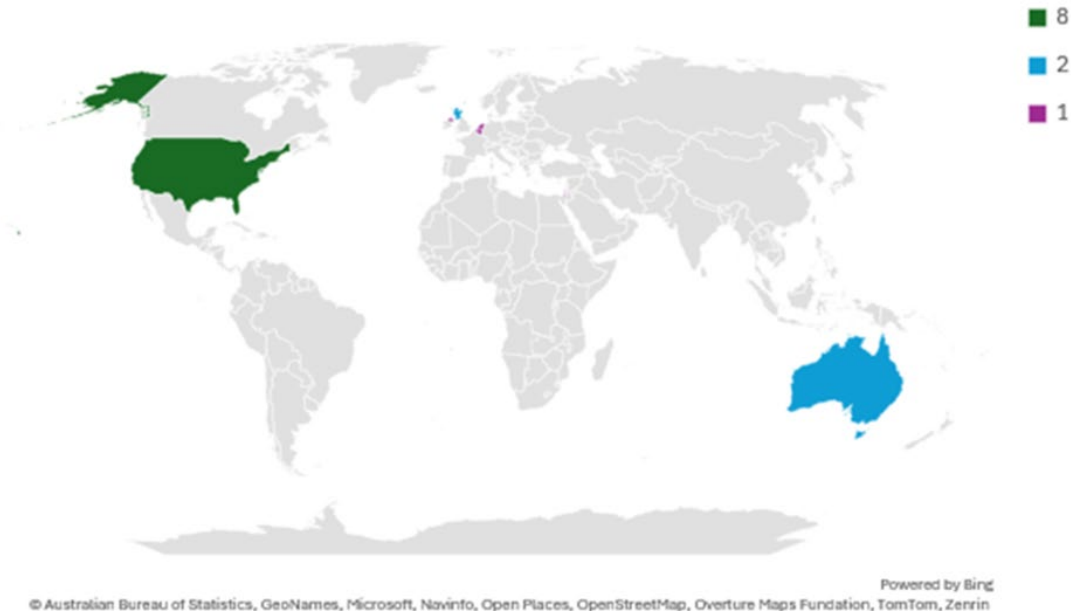
- Parents more influential and involved throughout adulthood in young peoples with ASD and ID, face more demands
- This research examines existing evidence-base on relationships and sexuality communication on ID and ASD.
- Scoping review to identify the barriers and enablers to parental communication and sought to outline any recommended programmes or interventions described in the included studies.

- Mak & Thomas' (2022) scoping review framework method for conducting a scoping review
- PRISMA-ScR guidelines followed



- Search terms devised using PICO framework
- **Databases searched:** Proquest Health Research Premium Collection, MEDLINE, PsychINFO, CINAHL
- **Exclusion criteria:** low income countries, non- parent communication, published before 2010, only included people >18.
- **Inclusion criteria:** English language, peer reviewed, people age <18, communication between parents and caregivers.
- **Analysis:** Braun and Clarke's (2006) thematic analysis applied.

Geographic Distribution of Research Paper Origins



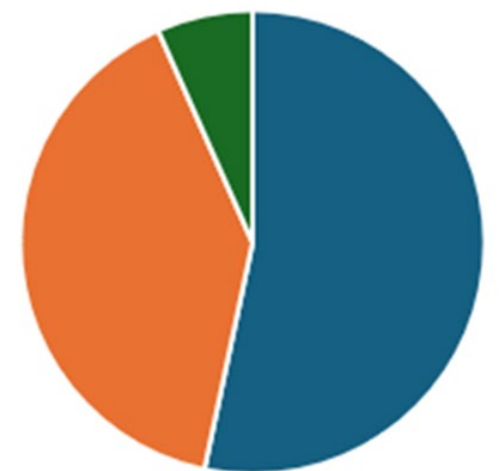
United States (n=8), Scotland (n=2), Australia (n=2), Netherlands (n=1)
Belgium (n=1), Northern Ireland (n=1), Israel (n=1).

Research Types



Semi-structured interviews (4) focus groups (3)
combination of focus group & one-to-one
interviews (3), mixed methods (1), observational
methods or surveys (3), feasibility study (1)

Count of Research Papers by Disability Focus



■ ID Only ■ ASD Only ■ ID and ASD

(8) ID only, ASD only (6), both ID and ASD (1),

Papers by Included Perspective



■ Parents perspective
 ■ Parents and children
 ■ Young people
 ■ Parents or family members and professionals working in ID

Parents perspective (9), both parents and their children (4), young people (1), parents or family members and professionals working in ID (1)

Parents' uncertainty
regarding children's
ability to understand
information

Belief that sexual
health information
wasn't relevant to
children's lives

Worry regarding
responses to sexual
health information

Lack of expertise on
the topic

Experience of societal
stigma attached to the
intersection of
disability and sexuality.



Communication Enablers

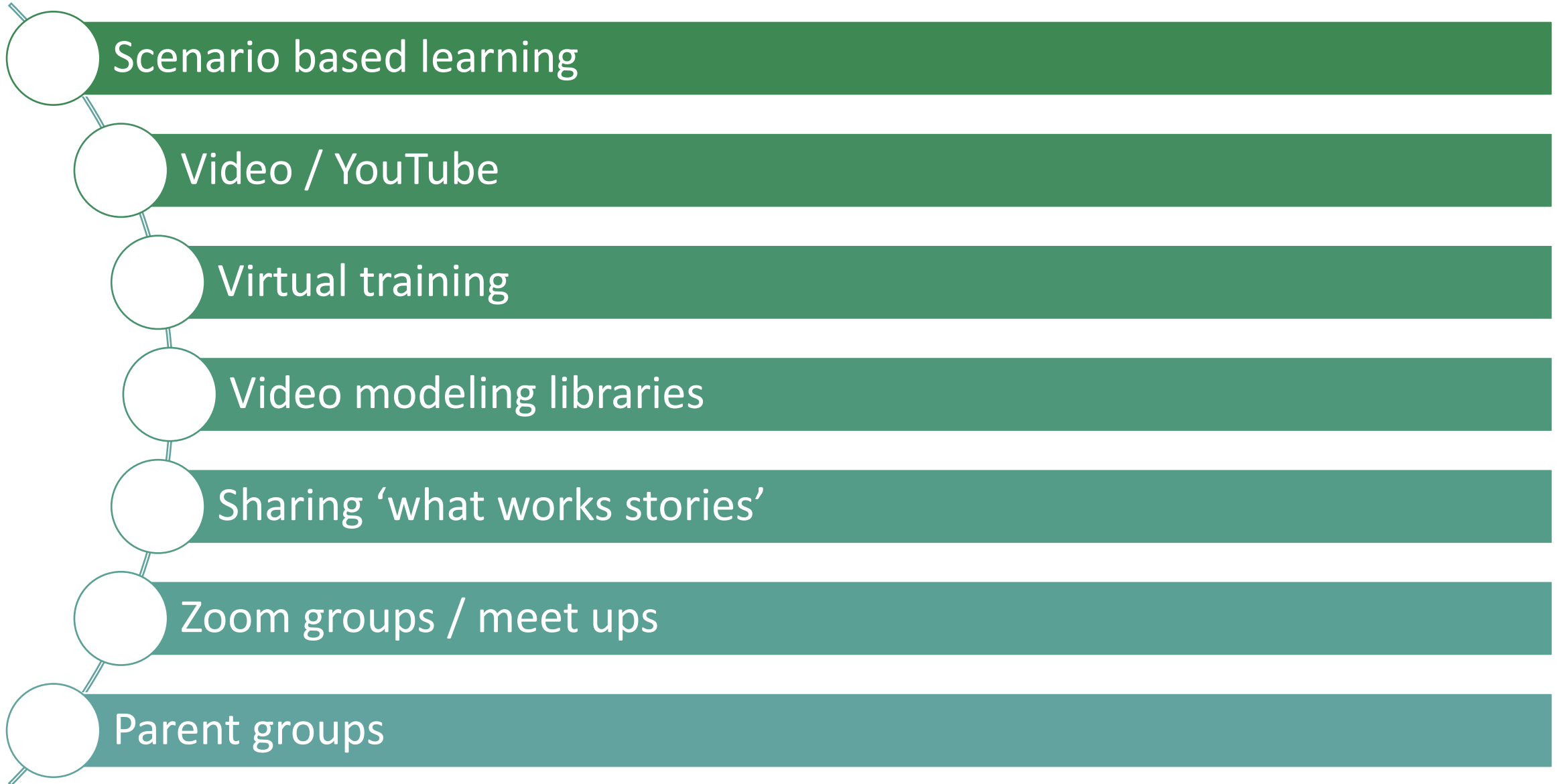


Parental desire to
communicate

Addressing personal
bias about sexuality

Adopting holistic
approaches to
sexuality

Accessing peer
support



- Need to support parents in teaching a holistic model.
- Need for social and communication skills alongside relationships and sexuality:
 - Navigate and understand social situations
 - Modelling relationships and dating initiation
 - Recognising the possibility and importance of romantic relationships

- Challenges faced in engaging in conversation and communication.
- Competing demands of caring for a child or young person with a disability
- Societal stigma experienced when discussing sexuality and disability
- Accessing appropriate resources.
- Highlights desire and willingness amongst parents and carers to learn and improve their confidence and skills and identifies resources that may support this.

- Barriers amenable to change via individual-level interventions and programmes.
- Right materials to provide information effectively.
- Attitudinal barriers and societal-level stigma may be slower to change.
- By addressing their own biases and attitudes, parents families and professionals can begin these conversations, and begin to advocate for policy and services in this important area.

- Michielsen, K. & Brockschmidt, L. (2021) Barriers to sexuality education for children and young people with disabilities in the WHO European region: a scoping review, *Sex Education*, 21:6, 674-692, DOI: 10.1080/14681811.2020.1851181
- Braun, V. and Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*. 3, 77-101 (2006)
- Mak, S. and A. Thomas, Steps for Conducting a Scoping Review. *J Grad Med Educ*. 14, 565-567 (2022)
- Tricco, A.C., et al., PRISMA Extension for Scoping Reviews (PRISMA-ScR): Checklist and Explanation. *Ann Intern Med*. 169, 467-473 (2018)
- World Health Organization, International Classification of Diseases (ICD-11). World Health Organisation Geneva (2019)



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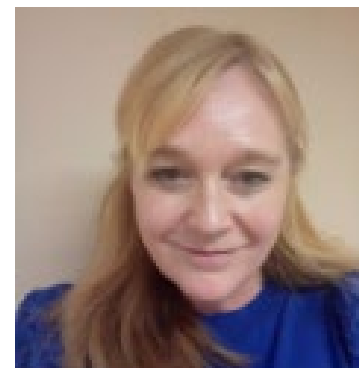
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