

# What is effective sex education for children and young people with intellectual disability?: A systematic review



**Presenting author**

**Dr Natasha Jojo**  
**Assistant Professor in Nursing**  
**Faculty of Health**  
**University of Canberra**  
[Natasha.jojo@canberra.edu.au](mailto:Natasha.jojo@canberra.edu.au)

**Dr Robyn Rosina**  
**Independent researcher**  
[Robynrosina@inet.net.au](mailto:Robynrosina@inet.net.au)

The image features a central yellow circle containing text. The background is split horizontally: the top half is black with a pattern of concentric dotted circles in shades of grey, and the bottom half is red with a similar pattern of concentric dotted circles. The yellow circle is centered and overlaps both background sections. The text 'ACKNOWLEDGEMENT' is arched across the top of the circle, and 'OF COUNTRY' is arched across the bottom. Inside the circle, there is a paragraph of text.

# ACKNOWLEDGEMENT

I would like to acknowledge  
the traditional custodians of this land.  
I pay my respects to the Elders  
past, present and emerging.  
For they hold the memories, the traditions  
and the culture of  
Aboriginal and Torres Strait Islander  
people across the nation.

# OF COUNTRY

# Why this research is important ?

- Sexuality is a central aspect of being human and is inseparably linked to overall health and well-being (Treacy et al., 2018).
- However, their attempts to express their sexuality are often repressed, considered inappropriate and controlled by others (Murray, 2019).
- Young people with intellectual disabilities are at high risk of abuse, but paradoxically often exempted from appropriate sexuality education (Murray, 2019).
- Existing programmes are not addressing their complex needs to feel safe and to express themselves (Treacy et al., 2018).

# What we wanted to know?

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1. What are the enablers and barriers for children and young people with intellectual disability to access sex education?

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2. What are the perspectives of carers about sex education?

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3. What are the most effective sex education teaching strategies and specific content for children and young people with intellectual disabilities?



# Method

## DATA BASES

MEDLINE

PsycINFO

Proquest

Cochrane  
Library

CINAHL

- Hand searching of reference lists.
- Reviewed relevant Grey literature
- 16 papers met search criteria

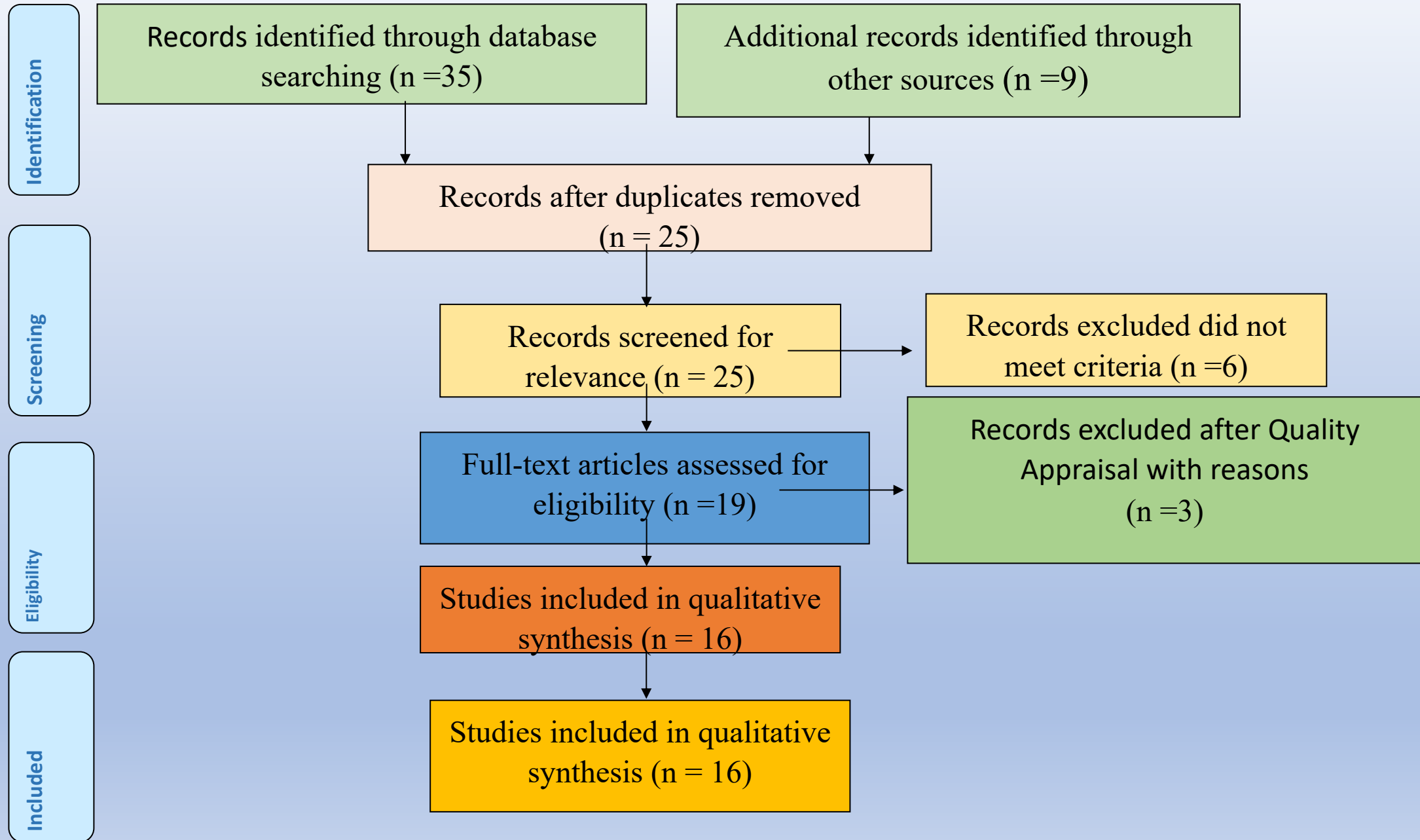
# Inclusion criteria

- All peer reviewed research studies in **English** published during **2011 to 2022** and which adopted **qualitative, quantitative, mixed method designs and systematic reviews** are included in the review.
- Studies conducted among **children and young people with Intellectual Disability (ID)** between **10-19** years and or, **their parents/carers** conducted in any settings, such as **school, community or health and social care settings** are included in the review.
- Studies evaluating the sexuality needs or specific sex education training programs focusing on children and young with ID, or their parents/carers were eligible to be included in the review.

# Exclusion criteria

- Studies focused on Physical disability, Autism, Autistic Spectrum Disorders, chronic disease, cerebral palsy are excluded from the review.
- Case studies and editorials have also been excluded.

# PRISMA chart





# Findings

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The findings of each of the studies were thematically analysed utilising an analytic inductive and reflexive approach (Braun & Clarke, 2006, 2019). The analysis categorised the findings into four themes.

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1. Barriers to effective sex education

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2. Delivery and content of sex education programs

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3. Young people's perspective of sex education

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4. Perspectives of parents of children with intellectual disability

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# What are the barriers to effective sex education

- Misunderstanding that children with intellectual disabilities are ‘**asexual**’ (Medina-Rico et al., 2018; Michielson & Brockschmidt, 2021; Nelson et al., 2019; Pownall et al., 2012; Rooks-Ellis et al., 2020).
- They are **often excluded** from the comprehensive sex education (Lofgren Martensson, 2012; Michielson & Brockschmidt, 2021).
- Teachers and carers **do not have specific skills**, policy and resources (Nelson et al., 2019).
- Teachers and carers in this situation are relegated to offer a ‘restrictive script’ of hetero-normative perspective of biology, limiting any opportunity for expression of **sexual diversity** or to learn about protective behaviours (Lofgren Martensson, 2012).

# What are the barriers to effective sex education

- **Difficulty to talk** about sex education (Apteslis, 2012; Kamaludin, Muhamad, Yudin& Zaharia, 2022; Kurtuncu, Kurt, 2020; Lofgren-Martensson, 2019).
- Lack of **parental awareness** (Miller, Pavlik, Kim & Rogers, 2017; Surekha, Indiramma, Girimaji, & Nair,2017).
- Very **diverse language and communicative abilities** as well as cognitive impairments (Lofgren-Martensson,2019).
- Lack of **reliable resources** ( Tsuda, Hartini, Hapsari & Takada, 2017).
- Gender-specific and associated **cultural barriers** (Gurol et al., 2014).

# Who would deliver sexuality education?

- A majority of parents preferred to be the first sexual educator of their children (Apteslis, 2019).
- Parental cooperation is a vital component of effective sexual abuse programs (Kim, 2016; Kucuk, Platin & Erdem, 2017; Kurtuncu & Kurt, 2020; Stein, Kohut & Dillenburg, 2018).
- Mothers focused on females and uncles focused on males (Phasha, & Runo, 2017)
- A mature individual endorsed by the local community 'sensitises' the young people about the responsibilities of sex, marriage and child-bearing. (Phasha, & Runo, 2017).
- SE is the task of teachers in the context of school (Kamaludin, Muhamad, Yudin & Zaharia, 2022; Lofgren Martensson, 2012; Stein, Kohut, & Dillenburg, 2018).

# What training method works?

- Role play was an effective teaching and learning strategy(Kim,2016 ;Warraitch, Amin, & Rashid, 2020).
- Teachers and learning assistants identify the puppet show as the most successful element of the training. ( Murray, 2019).
- Storyboards and visuals were very useful to engaging and learning( Murray, 2019)
- Short and frequent training sessions (Kim,2016)
- Repetition as vital for their children retain learning ( Murray, 2019)
- Prefer smaller 'girl and boy groups'( Lofgren Martensson, 2012)

# What should be the content of sex education ?

- Suggested content included empowering topics such as anatomy, health, personal hygiene, reproduction, the sexual response and expressions of love. (Stein, Kohut, & Dillenburger, 2018).
- Focused on concepts of sexual abuse and self protections skills (Thomas, Nattala, Shekhar, & Kumar, 2018).
- Favoured content was 'mechanisms of the bodies and differences between male and female' and sexually transmitted diseases, contraception unwanted exposure to pornography and avoiding high sexual situations (Tsuda, Hartini, Hapsari, & Takada, 2017; Lofgren Martensson, 2012).
- Sexuality and relationship education and information are required for young people with ID(Frawley, & Wilson, 2016).

# Young people's perspective of sex education

- Many participants were unsure if they had received sexual education (SE) and or by whom(Lofgren Martensson, 2012).
- Most sex education was about hygiene and menstruation, sexually transmittable diseases and contraception. Assessable sexuality and relationship education and information is required for young people with ID(Frawley, & Wilson, 2016).
- The majority wanted to learn about sexual functions and relationships matched to stages in their lives (Lofgren Martensson, 2012).
- Almost half wanted to receive SE from the most familiar person to them in the school(Lofgren Martensson, 2012).

# Perception of parents

- Most parents consider sexual education for young people as a human right and will have positive effects on family life (Apteslis,2019).
- SE was less necessary for their children with ID( Kamaludin, Muhamad, Yudin & Zaharia,2022;Lofgren-Martensson, 2019).
- Parents were fearful for their children's safety restricting their interaction with others. (Gurol et al., 2014;Apteslis, 2019;Kamaludin, Muhamad, Yudin, & Zaharia, 2022).
- School is the major social setting for these young people and the most opportune setting for learning about respectful relationships and sex education (Surekha, Indiramma, Girumaji & Nair et al 2017).
- Males devalue sex education viewing it as a private concern part of the domestic realm(Phasha & Runo, 2017).
- Parents concerned about vulnerability ( Kamaludin,Muhamad, Yudin & Zaharia, 2022;Kamaludin, Muhamad, Yudin & Zaharia,2022;Kurtuncu & Kurt, 2020;Miller, Pavlik, Kim & Rogers,2017;Surekha, Indiramma, Girumaji & Nair et al 2017; Stein, S., Kohut, & Dillenburg, 2018).



# Limitation

- Important studies might have been published in languages other than English, and these would have been missed in our search strategy.
- Limited sample size which makes generalization difficult
- There is a paucity of scientific literature about sex education

# Recommendations/conclusion

- There should be an opportunity to include young people with intellectual disabilities in sex education
- SE for children with ID require more strategies for teaching in a multicultural setting
- There is a need to develop evidence-based sex education programmes for children and their carers.
- More research is needed using role play of adults known to children(Kim,2016)
- Interventions should be incorporated into child education with a focus on parents, teachers, carers and awareness for the general public( Warraitch, Amin & Rashid, 2020; Miller, Pavlik, Kim, & Rogers, 2017).

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*Thank  
you*

