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Sexual exploration and people with an  
intellectual disability: Experiences of  
using the internet and outcomes of sex  
education programmes

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**(BSc Hons, MSc, Ph.D.)**

**Submitted in partial fulfilment of the requirements for  
the degree of**

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School of Health and Wellbeing

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*“Effortless is a myth, it’s only a point, life is bigger than the court”*

*Life lessons from Roger Federer (2024)*

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## **Chapter 1: Systematic Review**

**A systematic review focusing on content, delivery and outcomes of relationships and sex education programmes for individuals with a mild to moderate intellectual disability**

Prepared in accordance with the author requirements for Journal of Applied Research in Intellectual Disabilities (JARID)

[Journal Author Guidelines](#)

## **Abstract**

*Background:* Comprehensive quality education is critical to ensure that people with an intellectual disability can achieve sexual health and wellbeing. There remains a gap in the literature regarding the delivery, content and outcomes of relationship and sex education programmes for this population.

*Method:* This review synthesises findings from relationship and sex education programmes for individuals with an intellectual disability. PsycINFO, MedLine, CINAHL and ERIC were searched. PRISMA guidelines were followed, and the review registered with PROSPERO.

*Results:* The ten studies included in the review found improvements across knowledge, behaviour and skills. Delivery and content of the programmes varied widely, with a focus on protective behaviours. However, there were concerns about overall study quality.

*Conclusion:* The review highlights the complexity in determining the effectiveness of relationship and sex education programmes for people with an intellectual disability, in terms of improving knowledge, behaviour and skills.

*Key words:* intellectual disabilities, relationship and sex education, outcomes.

## **Lay Summary**

- The relationship and sex education programmes included in the review did appear to improve knowledge, behaviour and skills for people with a mild to moderate intellectual disability.
- The content of the education programmes and how they were delivered varied across the different studies.
- There was a greater focus on protective behaviours to prevent harm and less on sex, sexual identity, online dating and pornography.
- There were concerns about how the studies had been conducted; low numbers of people taking part, the questionnaires used to measure change were not well developed, statistical analysis could not be carried out in some studies because of low sample sizes and no comparison group was included in many of the studies.

## **Introduction**

The United Nations Convention of the Rights of People with Disabilities protects the right of people with an intellectual disability to have personal and sexual relationships (Equality and Human Rights Commission, 2017). Sexuality is a fundamental part of the human experience, yet people with intellectual disabilities face stigma and discrimination in developing and maintaining intimate relationships (Hole et al., 2022; Whittle & Butler, 2018). Central to achieving sexual health and sexual well-being is having access to comprehensive, good quality information along with knowledge about risks and self-protection (World Health Organisation, 2024). The right to relationships and sex education (RSE) is covered by the UNESCO International Guidelines, and should be accessible for all, which includes people with a mild to moderate intellectual disabilities (Department for Education, 2019).

The National Institute for Health and Care Excellence (2015) defines an intellectual disability as having a lower intellectual ability, (as seen in IQ tests) significant impairment of social or adaptive functioning and where the delays or difficulties begin in childhood. People with an intellectual disability present with difficulties with everyday tasks and their communication, social interaction and learning. There are four key classifications of intellectual disability: mild (approximate IQ range between 50-69), moderate (approximately IQ range between 35-49), severe (approximate range between 20 and 34) and profound (IQ under 20) (World Health Organisation, 2022). The American Psychiatric Association (2024) estimates that around 1% of the global population are affected although due to the different terminology used globally, this can be difficult to determine. In the UK, Public Health England (2016) estimate that approximately 2.16% of adults and 2.5% of children have an intellectual disability. Research has found a number of causes that contribute towards having an intellectual

disability; genetic syndromes such as Down Syndrome or Fragile X syndrome, meningitis, whooping cough, measles, head trauma in childhood, exposure to toxins, complications during pregnancy and birth as well as environmental factors such as the impact of alcohol or drugs during pregnancy (American Psychiatric Association, 2024; World Health Organisation, 2019).

Those with a mild or moderate intellectual disability will have some language and academic skills and will require less support than an individual with a severe and profound intellectual disability who will have limited language and academic skills and require daily support and supervision (Mencap, 2024). There is a lack of RSE programmes for individuals with a severe or profound intellectual disabilities due to the limited understanding and functioning in being able to make sense of the materials. Any content that is delivered for this population would be highly tailored to individual needs and is often focused on problematic behaviour (Grieve et al., 2007; Pérez-Curiel et al., 2024). Consequently, much of the research has focused on programmes for those with a mild to moderate intellectual disability.

Despite legislation and guidance in this area, some people with intellectual disabilities often feel that they are not receiving good enough RSE or that it is not positively framed (Frawley & Wilson, 2016). Previous research has also found that many people with intellectual disabilities do not receive RSE and, when asked, they find it difficult to remember even if they have received it (Schaafsma et al., 2017). A lack of RSE can make it more likely for people to practice unsafe sex and put them at greater risk of sexual abuse, victimisation and exploitation as well as increasing their risk of sexually transmitted diseases (Estruch-García et al., 2024; Mailhot Amborski et al., 2022; McDaniels & Fleming, 2016). Relationships have been found to improve quality of life and meaning to the lives of people with an intellectual disability, yet research has

consistently shown that this population lack knowledge and skills about relationships and sex (Baines et al., 2018; Jahoda & Pownall, 2014). This further highlights the importance for effective RSE for individuals with intellectual disabilities. RSE should expand into adulthood to take account of the challenges faced by this population across their life-course (McCann et al., 2019).

Research has shown that people with an intellectual disability can face multiple barriers when trying to access RSE programmes, concerns with delivery, content, attitude of parents and carers, and a lack of evidence on adaptation. Content can be delivered too quickly, not be accessible or comprehensible and focus on a single problematic behaviour or issues such as contraception or keeping safe (Hole et al., 2022; McCann et al., 2019). Moreover, few of those delivering RSE programmes will have received any training for delivering to this distinct group, and their attitudes can also play a role in determining the delivery of the programmes depending on their views about sex and relationships (Hole et al., 2022; McCann et al., 2019; Michielsen & Brockschmidt, 2021). The attitudes of parents and carers can also impact on the support given to engage in relationships (National Institute for Health Research, 2020). People with intellectual disabilities have placed importance on broader topics such as online relationships, social media, intimacy, pleasure and parenthood, which are not regularly covered in current education (Pérez-Curiel et al., 2024; Schaafsma et al., 2015). Additionally, there is also limited evidence about how RSE programmes should be adapted for this population. Tailoring the content to individual needs and using methods such as role-play, rehearsal and practice skills, has been found to be helpful in improving skills although many of these methods have not been empirically investigated (McDaniels & Fleming, 2016; Schaafsma et al., 2015).

There is some evidence that attending RSE programmes is helpful for those with intellectual disabilities, helping to improve both knowledge and behaviour (McCann et

al., 2019; Pérez-Curiel et al., 2024; Schaafsma et al., 2015). A recent meta-analysis by González et al. (2018) found that RSE programmes were effective but tended to focus on keeping people safe from abuse. Shorter sessions and more experienced staff delivering the programme were also associated with effectiveness. Wider benefits were also found for those attending RSE programmes with improvements in self-esteem, greater knowledge about sexuality and more positive feelings about sexual experiences (McCann et al., 2023).

Key gaps consistently identified in previous systematic reviews are the lack of information provided on what is covered in RSE programmes, how they are delivered and the relationship between content, delivery and outcome (Brown et al., 2020; McCann et al., 2019; Pérez-Curiel et al., 2024; Schaafsma et al., 2015). For example, Schaafsma et al. (2015) highlighted a need for a more detailed description of the programmes in order to examine which methods are effective for those with an intellectual disability. McCann et al. (2019) further emphasized a need to determine the programme structure, content and outcome measures captured of RSE programmes for this population. Additionally, Brown et al. (2020)'s systemic review concluded that there was a distinct need to examine the outcomes of RSE programmes. These points were all echoed in Pérez-Curiel et al. (2024) recent review.

This systematic review aims to address the gaps highlighted above by examining the content and delivery features of RSE programmes for people with intellectual disabilities, and their effectiveness in producing positive change in both knowledge and behaviour. The review seeks to answer the following questions;

- 1) What are the a) programme content and b) delivery features in relationship and sex education programmes for people with a mild to moderate intellectual disability?
- 2) When looking at knowledge and behaviour outcomes, how effective are relationship and sex education programmes for people with a mild-moderate intellectual disability?

## **Method**

The narrative synthesis systematic review was registered with PROSPERO (*registration number: CRD42024538048*) and followed the Preferred Reporting Items for Systematic Reviews and Meta-analysis (PRISMA) guidelines updated in 2020 (Page et al., 2021). *Appendix 1.1* shows the PRISMA checklist for this review. The guidelines recommend three distinct phases for the systematic review; the selection process according to the inclusion and exclusion criteria, quality assessment for the selected studies and data extraction to address the aim and research questions of the review.

### *- Search Strategy*

A search was conducted in four databases: PsycINFO, Medline, CINAHL and ERIC. The key terms for the search focused on three areas: 1) intellectual disability 2) sex and relationships and 3) education and training programmes. *Table 1* provides a summary of the different search terms used with searches taking place in March 2024. These were developed through adapting search terms used in the previous review by Paulauskaite et al. (2022) on outcome frameworks for RSE programmes for this population and from scoping the literature on regular terms used. This process included trialling search terms on each database to explore the subject headings and topic areas used. Search terms were adapted for each database and were combined to create search filters, search key headings, abstracts and titles. A subject librarian at the University of Glasgow reviewed



the search terms and provided advice on focusing the terminology. Theses and dissertations were excluded and only papers written in the English language were included. Full search terms for each database are included in *appendix 1.2*.

*Table 1. Search terms used in the systematic review.*

<b>Concept</b>	<b>Synonyms or related terms</b>
<b>Intellectual disability</b>	learning disab* or learning difficult* or learning disorder or learning impair* or intellectual* disab* or intellectual* impair* or intellectual dysfunction or development* disab* or development* disorder* or development* impair* or intellectual developmental disorder or mental* deficien* or mental* retard* or mental* handicap* or mental* disab* or mental insufficiency or mental* impair* or mental* challenged or IQ or subaverage intelligence or cognitive impair* or autis* or Asperg* or Down Syndrome or trisomy 21 or Smith-Magenis or Rett* or Lesch-Nyhan or Prader-Willi or Angelman or fragile X or Cri-du-chat or Cornelia de Lange or de Lange or Rubinstein-Taybi or special education* or special need* or additional support* or additional need*
<b>Sex and Relationships</b>	sex or sexuality or psychosexual behavio#r or sexual development or sexual health or psychosexual development or sexual behavio#r or psychosexual health
<b>Education</b>	education or training or curriculum or program*

- *Inclusion and Exclusion Criteria*

Inclusion and exclusion criteria were applied to the identified studies. Inclusion criteria were: a) young people and adults aged between 11 and 64, b) participants with a mild to moderate intellectual disability defined as by the ICD-11 as those who have an IQ between 35 and 69, c) studies concerning the evaluation of an RSE intervention / training/education programme, d) studies that included a quantitative method for measuring knowledge or behaviour outcomes pre- and post- intervention. Exclusion criteria were: a) studies where the intervention focused solely on inappropriate or harmful sexual behaviour, and b) where the intervention was delivered in secure accommodation or in hospital settings. Quantitative data from mixed methods studies were included in the review. Papers before 2000 were excluded during the screening process.

This was to reflect the changing attitudes and policies towards people with an intellectual disability and their rights and access to education and inclusion (Gates, 2001). Although the UN Convention of the Rights of Persons with Disabilities was not ratified until 2006, much of the foundational work began earlier marking this a pivotal point for this population (Harpur, 2012; Series, 2015). The late 1990s saw seminal pieces of work which helped shaped policy and practice; the World Health Organisation highlighting the challenges and barriers that people with disabilities experience with their reproductive rights and the Dakar Framework for Action 2000 and the Salamanca Statement and Framework for Action 1994 also promoting education for all (Agaronnik et al., 2020; Ainscow et al., 2019; Winzer & Mazurek, 2017). Capturing research from 2000 allows the review to focus on more relevant research which encapsulates the changing nature of relationship and sex education.

A wide age range was used because research highlighted the need for RSE to be taught to people with an intellectual disability across the lifespan (Dyer & das Nair, 2013; McCann et al., 2019). There would also appear to be few specific programmes for different age groups (Paulauskaite et al., 2022; Pérez-Curiel et al., 2024).

- *Second Reviewer*

An assistant psychologist working in the NHS acted as a second reviewer for both the screening and quality appraisal of papers. The second reviewer screened a randomly selected sample of 20% of the papers identified from titles and abstracts. Cohen's  $\kappa$  indicated substantial agreement between raters at this stage ( $\kappa=.634$ ). The second reviewer also randomly selected a sample of 20% of studies identified for full text inclusion, Cohen's  $\kappa$  indicated moderate agreement between raters, ( $\kappa=.600$ ).

Disagreements were discussed between the lead researcher and the second reviewer, and a consensus reached.

- *Data Extraction Plan*

Data were extracted from the selected papers to address the review questions. A data extraction spreadsheet was created using Microsoft Excel to record the following data from each study; type of study design, study country, study population (sample size, gender, age, level of intellectual disability, IQ if reported), information about the RSE programme (programme development, content and delivery features and, where relevant, techniques used for people with intellectual disabilities), the outcome measures (knowledge, behaviour or skills) the nature of the outcome measures used and the results of the outcome measurement. The age of participants was missing in Drew et al., (2023), this information was obtained from contacting the lead author.

- *Quality Assessment Plan*

Studies included in the review were appraised for their quality. For pre/post studies, the National Heart, Lung and Blood Institute (NHLBI) quality appraisal for before-after (pre-post) studies with no control group was used (National Heart Lung and Blood Institute, 2013). This tool focuses on study objectives, eligibility criteria, sample size, outcome measures, attrition rates and the use of appropriate statistical methods. For quasi-experimental studies and randomised controlled trials (RCT), the Joanna Briggs Institute (JBI) tools were used to assess study quality (Barker et al., 2024; Barker et al., 2023). For quasi-experimental studies, the tool focuses on internal and statistical validity and bias. For RCTs, the tool focuses on bias related to selection and allocation, assessment, detection and measurement of outcomes (if measures were taken in a reliable way and consistent for all participants), and statistical validity bias. Quality was assessed by two researchers independently and then discussed.

- *Synthesis of Findings*

Due to the range of outcomes used to investigate the outcomes of RSE programmes in the selected studies, it was not feasible to conduct a meta-analysis of the findings. Therefore, this review used a narrative synthesis approach which details the effects of interventions and the factors that impact on the delivery of them (Popay et al., 2006). Popay et al. (2006) set out four elements for a narrative synthesis:

1. The role of theory in evidence synthesis (for whom the intervention works)
2. Developing a preliminary synthesis
3. Exploring relationships within and between studies
4. Assessing the robustness of the synthesis

When applied to this review, the first step in the synthesis was to examine the features of the interventions included to gather information about whom they were delivered to, delivery features and what the outcomes were. A second step was to organise the results of the studies to describe patterns in the outcomes reported. This involved grouping studies by the intervention type, study design and by outcomes measured. The third step was to describe the differences and similarities between the studies and the outcomes.. Finally, all studies underwent a quality review process using published checklists according to study type. Data presented in the results section is a mixture of textual information of study characteristics, and tables detailing delivery features and outcomes measured.

## **Results**

- *Study Selection*

The search yielded 13,060 references. The PRISMA diagram in *Figure 1* summarises the study selection procedure. After removing duplicates and papers published pre-2000, 7,869 papers were then screened using their title and abstract. Of these, 41 papers were

found to meet the inclusion criteria and were included in the full-text review. 30 studies were excluded at the full-text screening stage due to a failure to report the participants' level of IQ or level of intellectual disability ( $n=8$ ) or because the participants did not have an intellectual disability ( $n=8$ ). Other papers were excluded because they were qualitative studies ( $n=6$ ), were not empirical studies ( $n=5$ ), or the study or participants were not suitable in some other way ( $n=3$ ). Ten studies were included in the review.

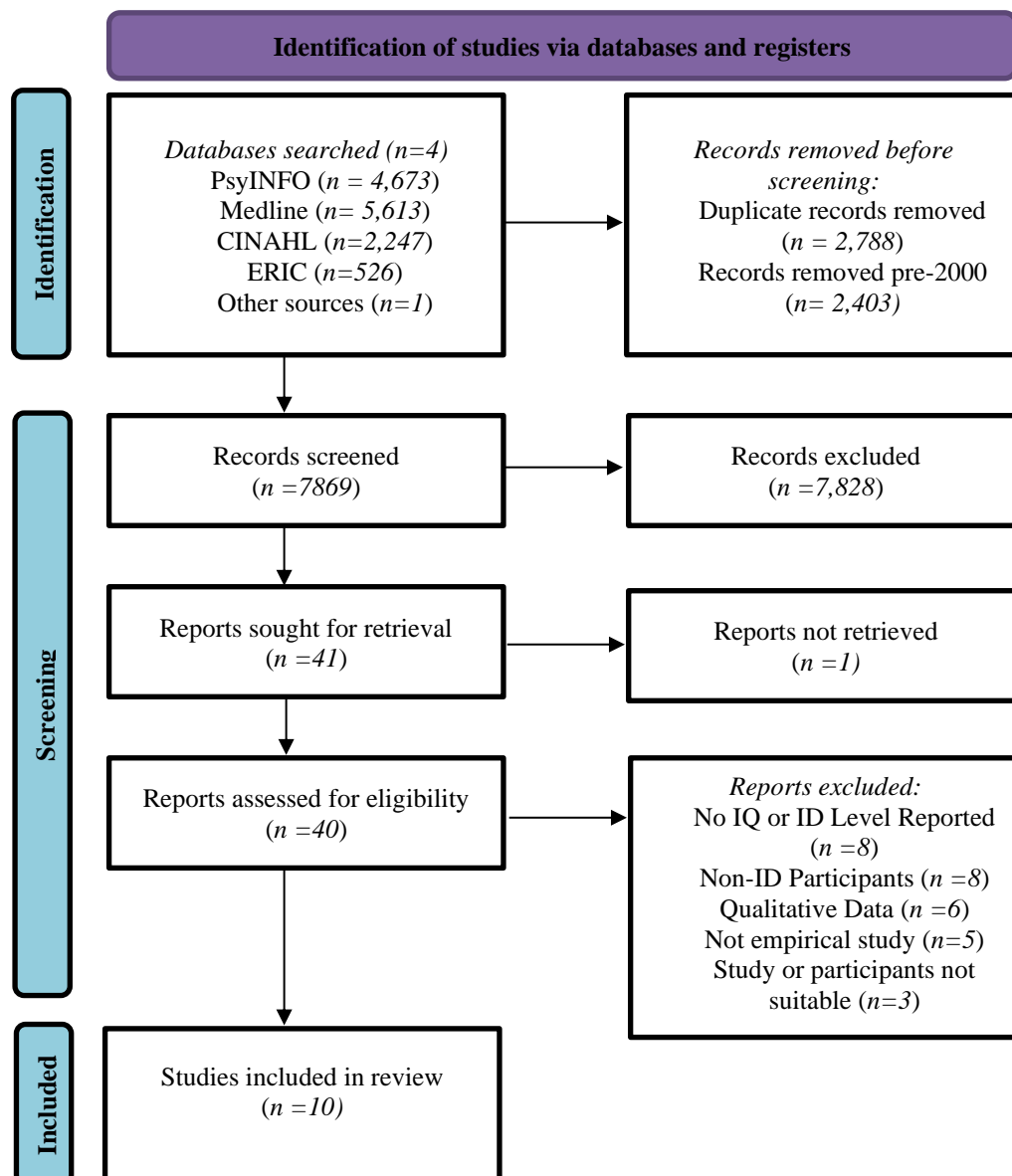


Figure 1. PRISMA Flow Diagram for study selection).

- *Study and participant characteristics*

The majority of studies did not have a control group ( $n=6$ ) (Box & Shawe, 2014; Drew et al., 2023; Dukes & McGuire, 2009; Garwood & McCabe, 2000; Gil-Llario et al., 2023; Sheppard, 2006), meaning that it was not possible to reach clear conclusions about the impact of attending RSE programmes on the participants' knowledge or behaviour. Three studies included a control group (Gil-Llario et al., 2024; Hayashi et al., 2011; van den Toren et al., 2022), and one study was an RCT (Kurt & Kürtüncü, 2024). Studies were conducted in eight countries, Australia (Garwood & McCabe, 2000; Sheppard, 2006) Spain (Gil-Llario et al., 2024; Gil-Llario et al., 2023), Turkey (Kurt & Kürtüncü, 2024), UK (Box & Shawe, 2014), Ireland (Dukes & McGuire, 2009), Japan (Hayashi et al., 2011), the Netherlands (van den Toren et al., 2022), and the USA (Drew et al., 2023). The sample sizes ranged from 4 to 254 with a total of 921 participants captured in this review. Only two studies reported on the ethnicity of their participants (Box & Shawe, 2014; Drew et al., 2023).

The majority of RSE programmes (80%) were delivered to both men and women. Only two studies focused on female participants (van den Toren et al., 2022) and one on male participants (Hayashi et al., 2011). Women constituted the majority of participants taking part in the studies, both in the intervention and control groups (63.19% female participants). The age range for the programmes ranged from age 11 to 67, with most studies focused on adult participants (Box & Shawe, 2014; Gil-Llario et al., 2024; Gil-Llario et al., 2023; Hayashi et al., 2011), two studies on young adults aged under 35, (Drew et al., 2023; Dukes & McGuire, 2009) one study including children and young adults (Garwood & McCabe, 2000), and two studies involving children (Kurt & Kürtüncü, 2024; Sheppard, 2006). One study (van den Toren et al., 2022) included both children and young adults up the age of 20.

The majority of studies included participants with a mild to moderate intellectual disability, with two studies including participants with a severe intellectual disability (Hayashi et al., 2011; Sheppard, 2006), and two studies also included participants who would be classed with a borderline intellectual disability (Drew et al., 2023; van den Toren et al., 2022). IQ score was not regularly reported; for the three studies that did report on IQ (Drew et al., 2023; Dukes & McGuire, 2009; Sheppard, 2006) IQ ranged between <40 to 79. One study while not explicitly stating the IQ levels of participants had set inclusion criterion that participants would have an IQ score between 50 and 85 with limitations in their adaptive functioning and social skills (van den Toren et al., 2022). A lack of information about the participants' level of cognitive functioning can make it difficult to draw conclusions about who RSE programmes might be suitable for.

- *Study Quality*

The NHLBI quality appraisal tool was used for the six papers with a pre-post study design (Box & Shawe, 2014; Drew et al., 2023; Dukes & McGuire, 2009; Garwood & McCabe, 2000; Gil-Llario et al., 2023; Sheppard, 2006). *Table 2* details the papers' quality ratings. The majority of papers were given a 'fair' rating due to having small non-representative samples of participants. Moreover, three of the studies (Dukes & McGuire, 2009; Garwood & McCabe, 2000; Sheppard, 2006) did not clearly describe and deliver the intervention consistently. The participants in Garwood and McCabe (2000) were split into two groups and received two different RSE programmes. In Dukes and McGuire (2009) the intervention was tailored to the individual but little information was provided on what the intervention consisted of.

Table 2. NHLBI quality appraisal ratings for pre-post studies. NR= Not reported.

	Garwood, & McCabe, (2000)	Sheppard, (2006)	Dukes, & McGuire, (2007)	Box, & Shawe, (2014)	Drew, et al. (2023)	Gil-Llario et al., (2023)
<b>Criteria</b>						
1. Study question or objective clearly stated	Yes	No	Yes	Yes	Yes	Yes
2. Selection criteria for the study population prespecified and clearly described	Yes	Yes	Yes	Yes	Yes	Yes?
3. Population in the study representative	No	Yes	No	No	No	Yes
4. All eligible participants that met the prespecified entry criteria enrolled	NR	NR	NR	NR	Unclear	No
5. Sample size sufficiently large	No	Yes	No	No	No	Yes
6. Intervention clearly described and delivered consistently	No	No	No	Yes	Yes	Unclear
7. Outcome measures prespecified, clearly defined, valid, reliable and assessed consistently	No	No	Yes	No	No	Yes
8. People assessing the outcomes blinded to the participants intervention	NR	No	NR	No	No	Yes
9. Loss to follow-up after baseline 20% or less	Yes	No	Yes	Yes	Unclear	NR
10. Statistical methods examine changes in outcome measures before and after intervention	N/A	N/A	N/A	N/A	Yes	Yes
11. Outcome measures of interest taken multiple times	No	No	Yes	No	No	No
12. Group Level: statistical analysis to determine effects at group level	N/A	N/A	N/A	N/A	No	Yes
<b>Rating</b>	<b>Poor</b>	<b>Poor</b>	<b>Fair</b>	<b>Fair</b>	<b>Fair</b>	<b>Good</b>

Three studies in the review adopted a quasi-experimental design with a control group, but without randomisation (Gil-Llario et al., 2024; Hayashi et al., 2011; van den Toren et al., 2022). *Table 3* details the JBI quality ratings for each criterion. The JBI checklist does not provide an overall rating of quality, but two raters judged each study against the criteria listed in the tool and scored each as Yes/No/Unclear/Not Applicable. In general,



these appeared to be good quality studies, but measurements were not collected in a reliable way in both Hayashi et al. (2011) and van den Toren et al. (2022) studies.

Table 3. JBI checklist for quasi-experimental studies.

		Hayashi et al., (2011)	van den Toren et al., (2022)	Gil-llario et al., (2024)
Criteria				
1.	Is it clear in the study what is the “cause” and what is the “effect”	Yes	Yes	Yes
2.	Was there a control group?	Yes	Yes	Yes
3.	Were participants included in any comparisons similar?	Yes	Yes	No
4.	Were the participants included in any comparisons receiving similar treatment/care, other than the exposure or intervention of interest?	Yes	Yes	Yes
	Were there multiple measurements of the outcome, both pre and post the intervention?	No	No Yes Yes	No No No
5.	Were the outcomes of participants included in any comparisons measured in the same way?	Yes	Yes Yes Yes	Yes Yes Yes
6.	Were outcomes measured in a reliable way?	No	Unclear Unclear Unclear	Yes Yes Yes
7.	Was follow-up complete and if not, were differences between groups in terms of their follow-up adequately described and analysed?	Yes	Yes Yes Yes	Yes Yes Yes
8.	Was appropriate statistical analysis used?	Yes	Yes Yes Yes	Yes Yes Yes

The RCT study (Kurt & Kürtüncü, 2024) was assessed using the JBI Checklist for RCTs; Table 4 shows the quality rating for each criterion for this study. Similar to the JBI checklist for quasi-experimental studies, this checklist does not provide an overall score or a rating of quality. Instead, the studies are rated on a number of criteria as being:

Yes/No/Unclear/Not applicable. A significant flaw in the study design is that mothers in the control group were given written information about the modules being covered in the intervention group therefore outcomes in this study may be underestimated as a result.

Table 4. JBI checklist for RCT study.

		Kurt & Kürtüncü, 2024)
<b>Criteria</b>		
1. Was true randomisation used for assignment of participants to treatment groups?		Yes
2. Was allocation to treatment groups concealed?		Yes
3. Were treatment groups similar at the baseline?		Yes
4. Were participants blind to treatment assignment?		Unclear
5. Were those delivering treatment blind to treatment assignment?		No
6. Were treatment groups treated identically other than the intervention of interest?		No
7. Were outcome assessors blind to the treatment assignment?	Outcome 1 Outcome 2	No No
8. Were outcomes measured in the same way for treatment groups?	Outcome 1 Outcome 2	Yes Yes
9. Were outcomes measured in a reliable way?	Outcome 1 Outcome 2	Yes Yes
10. Was follow-up complete and if not were differences between groups in terms of their follow-up adequately described and analysed?	Outcome 1 Outcome 2	Yes Yes
11. Were participants analysed in the groups which they had been randomised?	Outcome 1 Outcome 2	Yes Yes
12. Was appropriate statistical analysis used?	Outcome 1 Outcome 2	Yes Yes
13. Was the trial design appropriate, and any deviations from the standard RCT design (individual randomisation, parallel groups) accounted for in the conduct and analysis of the trial?		Yes

### Narrative Synthesis

The following section of the results synthesises the findings from the studies in terms of the RSE programme content, delivery features and the impact on knowledge and behaviour outcomes.

- *Design, Content and Delivery*

As seen in *table 5*, half of the studies in the review reported that their RSE programme focused on sex and relationships (Box & Shawe, 2014; Drew et al., 2023; Dukes & McGuire, 2009; Garwood & McCabe, 2000; van den Toren et al., 2022) with three studies reporting sexual health as their main focus (Gil-Llario et al., 2024; Gil-Llario et al., 2023; Kurt & Kürtüncü, 2024). One study focused on personal development (Sheppard, 2006) and another study on interpersonal behaviour within relationships (Hayashi et al., 2011). The majority of studies created bespoke programmes as part of their study with only two of the studies delivering the same intervention (Saludiversex) which applies a positive framework to sex education (Gil-Llario et al., 2024; Gil-Llario et al., 2023). Girls' Talk+ and Positive Choices are programmes designed for a population without an intellectual disability but were adapted for use for this population. Growing pains and Saludiversex were developed specifically for a population with an intellectual disability.

Most studies made reference to their programmes being based on previous education in the area (Box & Shawe, 2014; Dukes & McGuire, 2009; van den Toren et al., 2022). Three studies (two RSE programmes) were developed from previous literature (Gil-Llario et al., 2024; Gil-Llario et al., 2023; Sheppard, 2006). Drew et al. (2023) described their programme as being adapted from the Positive Choice curriculum and was based on the National Health Standards. One study described following cultural norms in order to create the programme and content and saw significant improvements in knowledge for those taking part (Hayashi et al., 2011). Lastly, Kurt and Kürtüncü (2024) described their programme as using the mastery learning model.

In terms of the target of the RSE programmes, the majority were aimed at adult participants (over the age of 18), with two other studies aimed at a wider age range

including adolescents and young adults (Garwood & McCabe, 2000; van den Toren et al., 2022) with only one study focusing solely on adolescents (Sheppard, 2006). Neither of the two papers including both adolescents and young adults made reference to taking the age range of their participants into account in the delivery of the programme.

In terms of the delivery of the programmes, as outlined in *table 5*, two RSE programmes were delivered by staff who were known to the participants both in Hayashi et al. (2011) and in the delivery of the Saludiversex programme (Gil-Llario et al., 2024; Gil-Llario et al., 2023). Interestingly, the Hayashi et al. (2011) study also used volunteers from the community to help deliver an element of the programme on conversational and communication skills. It was difficult to ascertain if training was provided for the individuals who delivered the programme ( $n=6$ ). The majority of studies ( $n=9$ ) used a group session format with only one study using an individualised approach (Dukes & McGuire, 2009). As detailed in *table 5* all RSE programmes but one were delivered weekly and the average number of sessions was 11, with a range from 6 to 20 weeks. The average length of session was 82.5 minutes (1.3 hours).

Table 5. Design and delivery of RSE programmes by studies.

	Name of RSE	Target/ Sample	Focus of RSE	Setting	Who delivered	Format	Timing	Session Length
<b>Garwood, &amp; McCabe, (2000)</b>	Bespoke (2 different programmes)	Adolescents/ Adults	<u>Sex Education</u> Body awareness, public and private body parts and behaviour, sexual relationships, protective behaviours, relationships and friendships, conception, pregnancy, childbirth, contraception, menstruation, HIV, feelings, body language, human life cycle	Day Centres	Educators	Group	6 or 10- weekly	1 or 2 hours
<b>Australia</b>	<u>Designed for population:</u> Yes	6 Male participants  <u>Age range:</u> 12-32  Mild Ability			<u>Training:</u> Unsure	<u>Topic N</u> 9-15		
<b>Sheppard, (2006)</b>	Growing Pains	Adolescents	<u>Personal Development:</u> Social skills, drug education, relationships and sexuality, protective behaviours, grieving and loss, human life cycle, personal hygiene	Education Setting	Teachers	Group	20- weekly	1 hour
<b>Australia</b>	<u>Designed for population:</u> Yes	48 Male 20 Female  <u>Age range:</u> 11-15  Mild, Moderate and Severe Ability			<u>Training:</u> Yes	<u>Topic N</u> 7		
<b>Dukes, &amp; McGuire, (2007)</b>	Bespoke	Adults	<u>Sex Education: Sexual Capacity</u> Safety practices, physical self, sexual functioning, choices, consequences in sexual matters.	Community Home	Researchers	Individual	Twice- weekly	45 minutes
<b>Ireland</b>	<u>Designed for population:</u> Yes	2 Male 2 Female  <u>Age range:</u> 22-23  Moderate Ability			<u>Training:</u> Unsure	<u>Topic N</u> 4		

<b>Hayashi et al., (2011)</b>	Bespoke	Adults	<u>Interpersonal Behaviour:</u> Body grooming and cleanliness, first impressions, communication, self-assertiveness, appropriate space, sexual harassment, male-female relationships, differences in male-female bodies	Community Home	Staff at home	<u>Group Topic N</u> 8	8-weekly	1 hour
<b>Japan</b>	<u>Designed for population:</u> Yes	24 Males 10 Males <u>Age range:</u> 19-45  Mild, Moderate, Severe Ability						
<b>Box, &amp; Shawe, (2014)</b>	Bespoke	Adults	<u>Sexuality and Relationships:</u> Anatomy and body differences, puberty, hygiene, menstruation, menopause, sexual activities, same-sex relationships, conception, contraception, safe sex, masturbation, wet dreams, self-examination, attraction, types of relationships, forming relationship, emotions, attitudes, good and bad touch, consent, public and private places, abuse, assertiveness.	Day Centre	LD Nurse	<u>Group Topic N</u> 23	10-weekly	2 hours
<b>UK</b>	<u>Designed for population:</u> Yes	3 Males 2 Females <u>Age range:</u> 20-49  Mild, Moderate Ability  Ethnicity: White British						
<b>van den Toren et al., (2022)</b>	Girls' Talk+	Adolescent and young adults	<u>Sexuality Education:</u> Knowledge, attitudes, self-efficacy, self-esteem, involving the social network	Education Setting	Trainers	<u>Group Topic N</u> 5	8-weekly (+parent session half-way)	1.5 hours
<b>Netherlands</b>	<u>Designed for population:</u> Adapted	249 Female <u>Age range:</u> 14-21						

		Mild, Borderline Ability						
<b>Drew, et al. (2023)</b>	Positive Choices	Adults	<u>Sex and Relationships:</u> Anatomy and physiology, puberty and adolescent development, identity, pregnancy and reproduction, sexually transmitted diseases and HIV, healthy relationships and personal safety	Education Setting	Graduates	Group	15-weekly	2 hours
USA	<u>Designed for population:</u> Adapted	5 Male 2 Female  <u>Age range:</u> 20-25			<u>Training:</u> Unsure	<u>Topic N</u> 7(+7)		
		Mild, Borderline Ability						
		Ethnicity: White						
<b>Gil-Llario et al., (2023)</b>	Saludiverse	Adults	<u>Affective Sexual Health Education:</u> Intimacy (public vs. private), self-care (STI prevention and contraception), autoeroticism (how, where, when), healthy couple relationships (respect and assertiveness skills), self-protection (identification of indicators of abuse and reporting skills).	Day Centre	Centre Staff	Group	16-weekly	2 hours
Spain	<u>Designed for population:</u> Yes	119 Male 135 Female  <u>Age range:</u> 19-67			<u>Training:</u> Yes	<u>Topic N</u> 4		
		Mild Ability						
<b>Gil-Llario et al., (2024)</b>	Saludiverse	Adults	<u>Affective Sexual Health Education:</u> Intimacy (public vs. private), self-care (STI prevention and contraception), autoeroticism (how, where, when), healthy couple relationships (respect and assertiveness skills), self-protection (identification of indicators of abuse and reporting skills).	Day Centre	Centre Staff	Group	16-weekly	
Spain	<u>Designed for population:</u> Yes	136 Male 110 Female  <u>Age range:</u> 21 to 64			<u>Training:</u> Yes	<u>Topic N</u> 4		

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		Mild, Moderate Ability						
<b>Kurt &amp; Kürtüncü, (2024)</b>	Bespoke	Adolescents	<u>Sexual Health and Development:</u> Private body parts, privacy, cleaning and hygiene, good-bad touch, behaviour support, foreign concept, safety limit.	Education Setting	Researchers	Group	8-weekly	30-40 mins
<b>Turkey</b>	<u>Designed for population:</u> Yes	25 Male 23 Female  <u>Age range:</u> 12-18			<u>Training:</u> Unsure	<u>Topic N</u> 8		
		Mild to Moderate Ability						

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The most common topic included in RSE programmes was protective behaviours which includes safe sex and was covered in all RSE programmes (*table 6*). Box and Shawe (2014) covered the highest number of topics in their group programme ( $n=13$ ), Garwood and McCabe (2000) covering ten different topics, however, this study included the delivery of two different RSE programmes which may explain the high number of topics.

Interestingly, Gil-Llario et al. (2023) and Gil-Llario et al. (2024) which both delivered the Saludiversex programme mentioned different topics. As seen in *table 6* it is noteworthy that consent was only explicitly mentioned in three RSE programmes (Box & Shawe, 2014; Dukes & McGuire, 2009; Kurt & Kürtüncü, 2024) although it may have been covered under the protective behaviours topic. Sex, including self-pleasure was included in five different RSE programmes (Box & Shawe, 2014; Dukes & McGuire, 2009; Gil-Llario et al., 2024; Gil-Llario et al., 2023; van den Toren et al., 2022). Puberty was covered in three RSE programmes (Box & Shawe, 2014; Drew et al., 2023; Garwood & McCabe, 2000) which were all targeted at adults with an intellectual disability and interestingly not covered by the RSE programmes which only targeted children (Kurt & Kürtüncü, 2024; Sheppard, 2006). Pornography and online dating were only covered in one study by Drew et al. (2023), and drugs education and loss were only included in Sheppard (2006). This study was designed for school children and included wider topics.

When looking at the content of the programmes by age of the participants, there was one key difference. The programme designed exclusively for adolescents (Sheppard, 2006) included a broader range of topics including content on grieving and loss as well as on drugs education, which were not covered by the programmes targeting adults only. However, other topics, such as puberty were delivered to adult participants in other programmes.

Table 6. Content of RSE programmes by study.

	Garwood, & McCabe, (2000)	Sheppard, (2006)	Dukes, & McGuire, (2007)	Hayashi et al., (2011)	Box, & Shawe, (2014)	van den Toren et al., (2022)	Drew, et al. (2023)	Gil-Llario et al., (2023)	Gil-Llario et al., (2024)	Kurt & Kürtüncü, (2024)
Protective Behaviours	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Public & Private Body Parts	✓			✓	✓			✓	✓	✓
Sexual Hygiene		✓		✓	✓			✓	✓	✓
Healthy (sexual relationships)	✓	✓		✓	✓		✓	✓		
Communication & Self-skills	✓	✓		✓		✓		✓	✓	
Human Body	✓	✓	✓	✓	✓		✓			
Sex (including self-pleasure)			✓		✓	✓		✓	✓	
Contraception	✓				✓		✓	✓		
Sexual Health	✓				✓		✓	✓		
Puberty	✓				✓		✓			
Sexual Identity					✓		✓		✓	
Consent			✓		✓					✓
Pregnancy	✓				✓		✓			
Feelings	✓				✓					
Drug Education		✓								
Grieving & Loss		✓								
Porn & Online Dating							✓			

Across the studies, there were a range of techniques used in the RSE programmes to help make them accessible for the participant group. A substantial proportion of studies used group discussions, videos, visuals, role-play and activities giving an opportunity for participants to practice the skills and knowledge being taught. There was a recognition that material needed to be tailored to the population group. As seen in *table 7*, only one study did not make reference to any techniques or adaptations made for the programme.

*Table 7. Techniques used across RSE studies.*

	<b>Techniques Used</b>
<b>Garwood, &amp; McCabe, (2000)</b>	Active experimental learning and didactic teaching strategies. Illustrative cards and videos.
<b>Sheppard, (2006)</b>	Visuals, multiple demonstrations, step by step instructions, group discussions, rules, activity video games, discussing worksheets.
<b>Dukes, &amp; McGuire, (2007)</b>	Individualised programmes targeting gaps. Use of worksheets, line drawings and dolls.
<b>Hayashi et al., (2011)</b>	Games, practice skills. External students were involved for conversational practice. Trust games, role-play, group work and field trips.
<b>Box, &amp; Shawe, (2014)</b>	None given.
<b>van den Toren et al., (2022)</b>	Active learning, modelling, discussion, consciousness raising, planning coping responses and repeated exposure, role-play, simple language, visual support, concrete examples given
<b>Drew, et al. (2023)</b>	Discussions, role-plays, didactic lessons, demonstrations, PowerPoint, pictures, YouTube Videos
<b>Gil-Llario et al., (2023)</b>	Visuals, social stories, modelling, role-playing, rehearsals/practice, group discussion, videos, models, group games
<b>Gil-Llario et al., (2024)</b>	Role-play, summary sheets, Visuals, social stories, modelling, rehearsals/practice, group discussion, videos, models, group games
<b>Kurt &amp; Kürtüncü, (2024)</b>	Drawings, PowerPoints, flash cards, real place pictures, story book, doll.

- *Outcomes*

As seen in *table 8*, the tools used for measurement varied across studies. The most common method for measuring outcomes was through self-reported questionnaires with two studies using a combination of both self-report and professional completed questionnaires (Gil-Llario et al., 2024; Gil-Llario et al., 2023), one study using a parent

and teacher checklist (Sheppard, 2006) and one study using a combination of both self-report and parent completed questionnaires (Kurt & Kürtüncü, 2024). As highlighted in *table 8* the majority of studies used established measures, but three studies developed bespoke measurement tools focusing on the topics covered in their particular programme (Drew et al., 2023; Sheppard, 2006; van den Toren et al., 2022), which presents validity and reliability bias concerns about the results of these studies. While not a standardised measure, van den Toren et al. (2022) adapted a questionnaire that had been used with girls without an intellectual disability by simplifying and shortening questions but no information is given on the reliability and validity of the measure. Hayashi et al. (2011) adapted the Scale of Social Skills (KiSS-18) for people with intellectual disabilities and ran a pilot survey prior to the study.

- *Knowledge based outcomes*

Knowledge was measured by tools focusing on sexual knowledge, for example, contraception, safety practices, friendship, sexual functioning in five of the studies (Box & Shawe, 2014; Drew et al., 2023; Dukes & McGuire, 2009; Garwood & McCabe, 2000; Kurt & Kürtüncü, 2024). However, as detailed in *table 8*, three of these studies had sample sizes too small to apply statistical analyses but described improvements from pre to post intervention for sexual knowledge (Box & Shawe, 2014; Dukes & McGuire, 2009; Garwood & McCabe, 2000). Dukes and McGuire (2009) was a unique study as it included multiple measurement points during the intervention as well as using an individualised intervention approach with participants. However, a small sample size and lack of information about content of the programme make it difficult to draw clear conclusions.

Two studies used inferential statistics to determine change from pre to post intervention. Drew et al. (2023) had a small sample size ( $n=7$ ) but found a significant average increase

( $p < .001$ ) on all topics asked about demonstrating a moderate effect as well significant knowledge increases on each individual topic as detailed in *table 8*. However, the use of unvalidated measures, being focused exclusively on the topics covered in the programme along with a small size raised concerns about the validity and reliability of the findings. Kurt and Kürtüncü (2024) used both self-report and parent completed measures and found that at post-test and follow-up, the intervention group had significantly higher in sexual knowledge scores (*post-test:  $p < .001$ , follow-up:  $p = .001$* ). Surprisingly, parents of the control group showed greater awareness of their children's sexual development at post intervention and follow-up than the parents of the intervention group (*post-test:  $p < .001$ , follow-up:  $p = .001$* ). Although this study had the most robust design with an RCT, information on the modules covered in the intervention group was shared with the mothers in the control group.

The evidence presented in the studies focusing only on knowledge, suggest that RSE programmes can improve overall sexual knowledge for participants. However much of this evidence comes from papers reporting descriptive information and not through the application of inferential statistics. Small sample sizes prevented these from being applied in a number of papers.

- *Knowledge and behaviour-based outcomes*

Three studies (Gil-Llario et al., 2024; Gil-Llario et al., 2023; van den Toren et al., 2022) examined sexual knowledge alongside measures of sexual behaviour or vulnerability however the results were mixed. Gil-Llario et al. (2023) did not include a comparison group but did include a validated tool to measure outcomes. They found a significant increase in knowledge of sexual practices for men only ( $p = .004$ ) and not for any other area of knowledge. In terms of behaviour, there was a significant decrease in sexual responsiveness for men ( $p = .027$ ). Younger participants' knowledge about homosexuality

increased ( $p=.015$ ) but there were no changes for any other knowledge domain and no significant changes in behaviour. Interestingly, participants who enjoyed greater autonomy demonstrated a significantly greater increase in knowledge about sexuality ( $p=.003$ ) than less autonomous participants but with no significant change in behaviour.

In a study of young females (van den Toren et al., 2022) which included a control group found that participants in the experimental group significantly increased their overall sexual knowledge ( $p<.001$ ), attitudes towards equal and voluntary sex ( $p=.026$ ) and overall self-efficacy ( $p=.033$ ) compared to the control group. No significant changes in behaviour outcomes were reported. However, the study used an unvalidated measure, adapted from a questionnaire used for people without an intellectual disability and not all outcomes were measured at every time point raising concerns with the validity of the results found.

Gil-Llario et al. (2024) also adopted a quasi-experimental design and used validated measures. As seen in *table 8*, their intervention group had significantly greater increases in sexual knowledge in general ( $p<.001$ ) indicating a moderate effect as well significant increases in specific topic areas as detailed in *table 8*. There were significant improvements for the experimental group in the risk of experiencing sexual abuse in general ( $p<.001$ ) indicating a medium effect. As highlighted in *table 8*, significant increases were also seen in particular topic areas for this domain. Measures completed by professionals also showed significant reductions for behaviour and knowledge in the experimental group (*behaviour:  $p=.005$ , privacy knowledge:  $p<.001$ , knowledge:  $p<.002$* ) indicating a moderate to large effect for these domains.

The evidence presented in these studies indicates that there were significant improvements in knowledge outcomes but less evidence to support a change in behaviour

outcomes. From these three studies, only sexual responsiveness in men (Gil-Llario et al., 2023) and concerns about behaviour saw significant change (Gil-Llario et al., 2024) but not on any of the other behaviour domains explored.

- *Skills*

Two studies measured social skills, protective behaviours, hygiene, communication and problem solving as their outcomes for the RSE programme (Hayashi et al., 2011; Sheppard, 2006). The RSE programme delivered in Sheppard (2006) was for school children and included a broader focus and found that all students increased their score on the personal development checklist. The greatest improvement was observed in social skills, relationship and sexuality and protective behaviours but less improvement on hygiene. However, the study did not use inferential statistics, nor a control group and used a self-developed tool to evaluate the programme, therefore the evidence presented was descriptive.

Hayashi et al. (2011) used a validated measure adapted for a population of adults with an intellectual disability. They included a control group and had sufficient sample size to carry out inferential statistics. They found statistically greater increases ( $p < .05$ ) in the social skills of the intervention group from pre to post intervention compared to the control group where there was no significant change. While baseline differences were not reported, the authors did comment that the control group had higher scores before the intervention than the experimental group. In the experimental group, only ten participants attended all sessions out of the group size of 17.

Preliminary evidence indicates that skills can be increased by RSE programmes however, only one of the studies included applied inferential statistics.

- *Outcomes and delivery features*

There was no clear pattern to the relationship between delivery features and change in outcomes for RSE programmes. All studies showed some improvements across the measures, but study quality was not robust enough for statistical analysis across all outcomes. When looking at the studies that conducted statistical analyses, more mixed effects were found for interventions delivered in educational settings (Kurt & Kürtüncü, 2024; van den Toren et al., 2022) than programmes in day centres and in community homes. In terms of who delivered the programmes, those delivered by professionals (Gil-Llario et al., 2024; Gil-Llario et al., 2023; Hayashi et al., 2011; Sheppard, 2006) who were known to the participants tended to find greater improvements in outcomes compared to studies involving unknown trainers or researchers. This might suggest that it was easier for the participants to engage with learning about a sensitive subject with people who they knew and trusted.



Table 8. Outcomes for RSE programmes by study.

	Method, Tool & Timing	Self-developed	Validated Measure	Statistical Analysis (N)	Outcomes Found
<b>Garwood, &amp; McCabe, (2000)</b>  <b>Outcome: Knowledge</b>	Interview & Scored  <u>Tool:</u> Sexual Knowledge, Experience, Feelings and Needs Scale for Intellectual Disabilities  <u>Timing:</u> Pre & Post	No	Yes	No (6)	<b>Knowledge &amp; Feelings:</b> Minimal increases in sexual knowledge from pre to post intervention.  Moderate increases in knowledge of friendship, marriage, sex, contraception, homosexuality, sex, pregnancy childbirth and STDs.  No average mean provided.
<b>Sheppard, (2006)</b>  <b>Outcome: Skills</b>	Parent and Teacher completed checklist  <u>Tool:</u> not named.  <u>Timing:</u> Pre & Post	Yes	No	No (90)	<b>All topics:</b> Improvements pre to post intervention.  Greatest improvement in social skills, relationships and sexuality, protective behaviours.  Least improvement in personal hygiene.
<b>Dukes, &amp; McGuire, (2007)</b>  <b>Outcome: Knowledge</b>	Self-reported questionnaire  <u>Tool:</u> The Sexual Consent and Education Assessment  <u>Timing:</u> Baseline, weekly during intervention and post	No	Yes	No (4)	<b>Areas of knowledge:</b> Improvements in safety practices, physical self, sexual functioning, choices and consequences.  <i>6-month follow-up:</i> 3 out of 4 participants showed maintenance scores for the safety scale and some reduction in scores on knowledge scale.  No increase from pre-post or follow-up on the inappropriate sexual behaviour scale.
<b>Hayashi et al., (2011)</b>	Self-reported questionnaire	Adapted for	Not for the population	Yes (34)	<b>Social Skills:</b> Significant increases for experimental group between pre and post intervention ( <i>Pre-test: M= 55.4, Post-test: M= 61.8, p&lt;.05</i> ).

<b>Outcome: Skills</b>	<u>Tool:</u> Scale of Social Skills  <u>Timing:</u> 1-month prior and 1-month post intervention	population (test survey)			No significant difference in control group from pre to post ( <i>Pre-test: M= 69.3, Post-test: M= 65.7, p&gt;.05</i> ).
<b>Box, &amp; Shawe, (2014)</b>	Self-reported questionnaire	No	Unknown	No (5)	<b>Social and sexual knowledge:</b> Increase in scores. Total score increase ranged from +5 to +18 for participants.
<b>Outcome: Knowledge</b>	<u>Tool:</u> not named.  <u>Timing:</u> Pre & Post				Generally better knowledge on social aspects than on sexual knowledge
<b>van den Toren et al., (2022)</b>	Self-reported questionnaire	Yes	No	Yes (249)	<b>Sexual Behaviour:</b> No significant differences reported. Not all questions asked at post-test
<b>Outcome: Knowledge &amp; Behaviour</b>	<u>Tool:</u> not named.  <u>Timing:</u> Pre & Post & 3-month Follow-up				<p><b>Sexual Victimization:</b> No significant differences reported.</p> <p><b>Overall sexual knowledge:</b> Statistically significant increase from pre-test to post test in the experimental group compared to control, (<math>B=1.04</math>, 95% CI= 0.65, 1.51, <math>p&lt;.001</math>). Adjusted model showed significant increase, (<math>B=0.60</math>, 95% CI= 0.13: 1.08, <math>p=0.13</math>) for intervention group compared to control.</p> <p><b>Attitudes towards equal and voluntary sex:</b> Statistically significant increase between post-test among girls in the intervention compared to control, (<math>B=0.15</math>, 95% CI= 0.02: 0.28, <math>p=.026</math>).</p> <p><b>Overall self-efficacy:</b> Statistically significant increase between post-test and follow-up among girls in the intervention compared to control, (<math>B=0.13</math>, 95% CI- 0.01:0.25, <math>p=.033</math>). Adjusted model showed significant increase, (<math>B=0.12</math>, 95% CI= 0.01: 0.23, <math>p=0.42</math>) for intervention group compared to control.</p> <p><b>Self-esteem:</b> No significant differences reported.</p> <p><b>Asking for help:</b> No significant differences reported.</p>

					<b>Overall intervention effect:</b> Significant group by time interaction: <i>Wilks Lambda</i> = .843, <i>F</i> (2, 245) = 3.52, <i>p</i> < .001, $\eta^2$ = .171
<b>Drew, et al. (2023)</b>	Self-reported questionnaire	Yes	No	Yes (7)	<p><b>All topics:</b> Significant increase on all topics (relationship and self-awareness (<math>d=1.36</math>), maturation (<math>d=2.07</math>), the life cycle (<math>d=1.37</math>), sexual health (<math>d=1.68</math>), being strong and staying strong (<math>d=1.54</math>) areas from pre to post intervention (<math>p &lt; .005</math>))</p> <p><b>Average Scores:</b> Significant increase on average scores from pre (<math>M=55.54</math>) to post-intervention (<math>M=77.61</math>), <math>t(6) = 7.79</math>, <math>p &lt; .001</math>, <math>d=4.47</math></p>
<b>Outcome:</b> <b>Knowledge</b>	<p><u>Tool:</u> not named.</p> <p><u>Timing:</u> Pre &amp; Post</p>				
<b>Gil-Llario et al., (2023)</b>	Self-reported questionnaire & Professionals questionnaire	No	No	Yes (254)	<p><b>Gender:</b> Men had a significantly greater increase in their knowledge of sexual practices compared to women, (<math>\beta_{10}=0.65\pm0.22</math>, <math>p=0.004</math>). Men had a significant decrease in their sexual responsiveness compared to women, (Sexual response: <math>\beta_{10}=0.34\pm0.15</math>, <math>p=0.027</math>). No other differences on sexual knowledge or sexual behaviour.</p> <p><b>Age:</b> Statistically significant difference in younger participants who had a significantly greater increase in knowledge in homosexuality, compared to older participants, (Homosexuality: <math>\beta_{10}=-0.01\pm0.005</math>, <math>p=0.015</math>). Professionals showed statistically significant differences in the concern for their client's behaviours in favour of older participants (<math>\beta_{10}=0.01\pm0.002</math>, <math>p=0.044</math>). No other differences on sexual knowledge or sexual behaviour.</p> <p><b>Autonomy:</b> More autonomous participants showed a significantly greater increase in knowledge about sexuality in general and sexuality to a greater extent than participants who were less autonomous, (Total scale: <math>\beta_{10}=1.49\pm0.73</math>, <math>p=0.043</math>; Concept of sexuality: <math>\beta_{10}=0.47\pm0.16</math>, <math>p=0.003</math>). No other differences on sexual knowledge or sexual behaviour.</p> <p><b>Partner:</b> No significant difference on knowledge about sexuality post-intervention depending on having a partner or not.</p>
<b>Outcome:</b> <b>Knowledge&amp; Behaviour</b>	<p><u>Tool:</u> Self-report Instrument for the Assessment of Sexual Behaviour and Concerns of People with Mild Intellectual Disabilities</p> <p><u>Tool:</u> Inventory of Sexual Knowledge of People with Intellectual Disability</p> <p><u>Tool:</u> Assessment of Sexual Behaviour and Knowledge of People with Intellectual Disability</p>				
	<u>Timing:</u> Pre & Post				

<b>Gil-Llario et al., (2024)</b>	Self-reported questionnaire & Professionals questionnaire	No	Yes	Yes (246)	<p><b>Sexual Knowledge:</b> Statistically significant differences between groups on knowledge about homosexuality, (<math>\beta_{10} = 0.96 \pm 0.14, p &lt; .001</math>), dating, intimacy and sexual assertiveness (<math>\beta_{10} = 1.21 \pm 0.34, p = .002</math>), sexual health (<math>\beta_{10} = 1.65 \pm 0.17, p &lt; .001</math>), and for total sexual knowledge general? (<math>\beta_{10} = 2.71 \pm 0.88, p = .011</math>) from pre-test to post-test.</p>
<b>Outcome: Knowledge &amp; Behaviour</b>	<p><u>Tool:</u> Inventory of Sexual Knowledge of People with Intellectual Disability</p>				<p><u>Effect sizes:</u> Homosexuality: (<math>d = 0.85; 95\% CI = 0.51, 1.18</math>); Dating, intimacy, and sexual assertiveness: <math>d = 0.82; 95\% CI = 0.49, 1.15</math>; Sexual health: (<math>d = 1.24; 95\% CI = 0.89, 1.59</math> and for total scale (<math>d = 0.76; 95\% CI = 0.44, 1.09</math>)). The domains of sexuality concepts (<math>d = 0.71; 95\% CI = 0.38, 1.03</math>) and body image and sexual communication (<math>d = 0.67; 95\% CI = 0.34, 0.99</math>) presented moderate and significant effect sizes.</p>
	<p><u>Tool:</u> Detection of Sexual Abuse Risk Screening Scale</p>				<p><b>Risk of experiencing sexual abuse:</b> Significant improvements for experimental group in risk factors and self-protection skills, (<math>\beta_{10} = -5.02 \pm 0.27, p = .003</math>), lack of awareness of intimacy rules, (<math>\beta_{10} = -0.62 \pm 0.18, p = .003</math>), risk of experiencing sexual abuse in general (<math>\beta_{10} = -6.16 \pm 0.52, p &lt; .001</math>) compared to control group.</p>
	<p><u>Tool:</u> Assessment of Sexual Behaviour and Knowledge of People with Intellectual Disability</p>				<p><u>Effect sizes:</u> Risk factors and self-protection skills (<math>d = -2.75; 95\% CI = -3.14, -2.36</math>), Lack of awareness of intimacy rules (<math>d = -0.41; 95\% CI = -0.7, -0.12</math>) and for the total scale (<math>d = -1.86; 95\% CI = -2.2, -1.52</math>)</p>
	<p><u>Timing:</u> Pre &amp; 2 weeks post intervention</p>				<p><b>Professionals Perspective:</b> Significantly decreased for experimental group for inappropriate of uninhibited sexual behaviour &amp; interpretation of their sexuality, and risk of posing misconceptions or experiencing loneliness and sexual abuse compared to control group, (<math>\beta_{10} = -0.34 \pm 0.11, p = .005</math>). Significant increase in knowledge about privacy and social norms of the experimental group post-test compared to the control group (<math>\beta_{10} = 0.96 \pm 0.15, p &lt; .001</math>). A significant increase in knowledge about sexuality, (<math>\beta_{10} = 1.54 \pm 0.43, p &lt; .002</math>). No significant difference in reported concerns about sexuality for people with an intellectual disability.</p>
					<p><u>Effect sizes:</u> professionals' perception of people with intellectual disabilities knowledge about sexuality (<math>d = 0.81; 95\% CI = 0.53, 1.08</math>) and about privacy and social norms (<math>d = 1.1; 95\% CI = 0.82, 1.38</math>). Inappropriate or uninhibited sexual behaviour of the people with intellectual disability (<math>d = 0.054; 95\% CI = -0.81, -0.28</math>)</p>

<b>Kurt &amp; Kürtüncü, (2024)</b>	Self-reported questionnaire & Parent completed questionnaire	Yes (self-report measure)	Yes- both	Yes (48)	<b>Self-reported knowledge:</b> Post intervention, the experimental group ( $M=29.79$ ) had significantly a higher score than the control group ( $M=20.54$ ), $p<0.001$ .
<b>Outcome: Knowledge</b>	<u>Tool:</u> Sexual development knowledge assessment scale for children with intellectual disabilities	No (parent/carer report)			At follow-up, the experimental group ( $M=28.25$ ) had a significantly higher score than the control group ( $M=20.58$ ), $p=0.001$ .
	<u>Tool:</u> Sexual development characteristics of children with adolescent intellectual disability Scale				Education group experienced significantly greater increase in knowledge compared to the control group ( $F=8.87$ , $p=0.001$ ).
	<u>Timing:</u> Pre-intervention, post-intervention, 1-month follow-up				<b>Parent/Carer reported sexual development:</b> Post-intervention, control group ( $M=136.20$ ) had significantly higher scores than the experimental group ( $M=123.33$ ), $t=-4363$ , $p<0.001$ .
					At follow-up the control group ( $M=137$ ) had significantly higher scores than the experimental group ( $M=123$ ), $t= 3.734$ , $p<0.001$ .
					Maternal awareness had a greater increase in the education group than in the control group ( $F= 13.89$ , $p= 0.001$ ).

## **Discussion**

The main aim of this systematic review was to examine the content, delivery and outcomes of RSE programmes for individuals with a mild to moderate intellectual disability.

The majority of programmes included in the review were for adults which suggests that RSE is required for people with intellectual disabilities across their life course (Dyer & das Nair, 2013; Nyokangi & Phasha, 2016). There was only one programme that focused solely on adolescents and two programmes which included a wider age range of both adolescents and young adults. This review did not find evidence that content had been tailored to specific age groups, as there was a range of topics covered across all RSE programmes. This suggests that age groups were often placed together. However, it has been acknowledged in the literature that content should be developed for a specific age range; there is a need to fully explore what people with an intellectual disability at different stages of life want covered in RSE programmes (Schaafsma et al., 2015).

It was difficult to ascertain from the studies how much training those delivering the interventions had received. Given that, previous research has found that training and experience are linked to effectiveness, missing this information prevents consideration of a key factor (González et al., 2018). As seen in general sex education literature, the person delivering the RSE programme has a crucial role to play (Renold et al., 2023). In this review, positive outcomes were seen when the programme was delivered by someone known to the participant. This suggests that participants might find it easier to engage with sensitive topics like RSE when it is delivered by people they know and trust. This may also make it easier to adapt material appropriately. This is reflected in evidence from RSE programmes for young people without intellectual disabilities which has indicated

a desire for parents and carers to take a more prominent role in teaching and talking about sex, sexuality and relationships (Hollis et al., 2022).

Most studies were designed on previous findings in the area; either from the evidence base about what to include in RSE or from previous education delivered, rather than on specific theory. Only one study referred to a theory of learning informing the design of the programme. These findings support previous literature that has found that RSE programmes are being developed designed specifically for this population, but that there has been a lack of programmes based on theory (Brown et al., 2020; Pérez-Curiel et al., 2024).

Studies reported on the interactive techniques they used to deliver the programme, with role-plays and visual materials being a common method, in line with previous research (Schaafsma et al., 2015). This review has found that programmes used interactive methods for delivering the content, supporting a previous finding that didactic techniques may be an ineffective teaching method for people with intellectual disabilities (McDaniels & Fleming, 2016). The most common topic across RSE programmes was protective behaviours with all programmes covering this topic and less focus on sexual identity, sexual orientation, pornography and online dating. This supports earlier research that RSE has focused more on keeping safe than other topics, however, people with an intellectual disability would welcome broader content and value information on online dating and pornography as well as on sexual orientation (Pérez-Curiel et al., 2024; Schaafsma et al., 2015). It remains a key challenge as to how to adapt RSE programmes, and tailor them to the specific needs of the population (McDaniels & Fleming, 2016).

While all studies demonstrated some improvements across knowledge, behaviour and skills-based outcomes, there was some variation across each domain. Those studies

focused on improving sexual knowledge added to the research base showing that there is strong evidence that RSE programmes can improve sexual knowledge (Pérez-Curiel et al., 2024). However, there was a lack of studies and limited evidence of change in sexual behaviour or vulnerability which is in line with previous research (McCann et al., 2019; Paulauskaite et al., 2022; Pérez-Curiel et al., 2024).

This review contrasts earlier research which had found no RSE programmes aimed at teaching skills. In this review, this is an area showing preliminary evidence in improvement in skills, but more research is needed to explore this further (González et al., 2018; Paulauskaite et al., 2022). However, across the review, there were substantial concerns about study quality. Small sample sizes, lack of comparison groups, the use of unvalidated measures and limited use of inferential statistics made it difficult to draw conclusions about the interventions. Many of the studies used bespoke questionnaires, developed to address the topics covered in the interventions. While this is a pragmatic approach to measuring change in a service context, it brings into question the validity and reliability of the findings (Pérez-Curiel et al., 2024).

- *Limitations*

There are several limitations to this review. Firstly, while every effort was taken to keep search terms broad due to the variation in the terms used, there is a possibility that relevant papers were missed. A number of papers had to be excluded due to a lack of information on the severity of the participants' intellectual disability. Having clear information about participants' level of intellectual disability would have enabled a more comprehensive review and would also provide a clearer understanding about who the interventions were designed for. Secondly, this systematic review only included peer reviewed papers and did not include grey literature, or theses or dissertations. As this field has a growing evidence base, other sources may be available if the inclusion



criteria were broader. Thirdly, the review did not include RSE programmes for those with severe intellectual disability who are an under-represented group in research on sex education (Pérez-Curiel et al., 2024). There was also an absence of information provided about the sample in each of the studies. This included a lack of data about participants' ethnicity, living situation or inclusion in previous RSE education. Lastly, this review focused on quantitative measures and may have missed important findings about the acceptability of RSE programmes which would be captured using qualitative measures.

- *Strengths*

This systematic review has several key strengths. Firstly, it addresses a gap in the literature around the content and delivery of RSE programmes for individuals with a mild to intellectual disability. It has provided a comprehensive description of the content included in the RSE programmes which has not been done in a previous systematic review. Secondly, it supports previous evidence that these programmes create change in terms of the outcomes measured.

- *Implications for practice, research and policy*

The current review has highlighted several implications for both practice and research. Firstly, the content of the relationships and sex education programmes from the studies in this review were mainly focused on self-protection measures. There is a distinct need for a broader content in programmes to capture the changing world, including information on online dating, social media and taking a positive stance to people's sexuality and sexual needs (Pérez-Curiel et al., 2024; Schaafsma et al., 2017). Secondly, this review has clearly highlighted a need for more robust evidence to be able to draw clear conclusions about RSE programmes and their outcomes. Detailed information should also be included in studies about participants, the delivery features, the content of

the programmes and how they are adapted for people with intellectual disabilities. Thirdly, higher powered randomised studies using validated measures would allow evidence of effectiveness to be obtained.

In terms of policy implications, this review has highlighted the variation in content covered in RSE programmes. It has provided a detailed synthesis which can help future policy to provide guidance and advice on the topics covered in these programmes. It has also highlighted the variation in delivery features of RSE programmes and has provided preliminary evidence for which approach influences outcomes providing helpful information for influencing policy on how best to design and deliver RSE programmes for people with a mild to moderate intellectual disability. This indicates that future RSE programmes for this population should focus on a broad range of topics and skill developed as well as different methods employed as part of the programme. Outcomes for these programmes should be evaluated through the use of validated measures according to the aim of the programme. The results further demonstrated that there is a lack of age specific content of RSE programmes for this population, with large age ranges in many of the studies captured. Therefore, there needs to be further work to explore what content needs to be taught across the lifespan.

In conclusion, this narrative systematic review has provided a detailed account of the content, delivery and outcomes of RSE programmes for people with a mild to moderate intellectual disability. It has highlighted numerous concerns with study quality which make it difficult to draw conclusions about outcome change. Future research should focus on building a stronger evidence base to provide key information about topics to be included and how best to deliver to those with an intellectual disability.

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## **Chapter 2: Major Research Project**

**The good, the bad and the sexy: A qualitative study of the experiences of young adults with mild to moderate intellectual disabilities use of the internet for sexual exploration**

Prepared in accordance with the author requirements for Journal of Applied Research in Intellectual Disabilities (JARID)

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## **Plain Language Summary**

*Background:* The internet has changed the way we live. It is used to create and build connections with other people both for friendships and intimate relationships, and to find things out about sex. However, we know that people with an intellectual disability do not have the same level of access and use of the internet compared to people without a disability. Research has also found that this group have high rates of loneliness and social isolation, but the internet could be a tool to help bridge this gap. The aim of this research was to look at the ways that young adults with an intellectual disability use the internet to find things out about sex and relationships.

*Aims:* This study aimed to ask young adults with intellectual disabilities about their social media use, the different apps they used, and their use of the internet to find things out about sex and relationships.

*Methods:* Seven young adults with mild to moderate intellectual disabilities, aged between 18 and 26 took part in the study. They were recruited from higher education colleges in the Scottish Highlands to take part in a research interview. Each person was interviewed in-person individually by the researcher who asked them about the devices they owned, what social media apps they used, how the content they saw related to sex and relationships and how they used the internet to explore sex and relationships. Before the interview took place, informed consent was obtained. During the interview, a social media app logo quiz was used to help prompt discussion and put participants at their ease. At the end of the interview, participants completed two learning tasks to find out more about the participants' ability. Participants were given a £10 amazon voucher to thank them for their time. Interviews took place between November 2023 and March 2024. The interviews were recorded and analysed using reflexive thematic analysis. This is a way

of looking in detail at what people said to try and get an in-depth understanding of their experiences.

*Results:* People who took part in the study used different social media apps. The most commonly used apps were WhatsApp, Messenger and TikTok. There were five main areas that people talked about. Firstly, participants said that social media helped them feel connected with others. They enjoyed using the internet to keep in touch with people they already knew and to build new friendships and relationships. Secondly, some participants used the internet to try and meet someone to have an intimate relationship with. Thirdly, most participants did not think that pornography was for them, and it was hard for them to talk about why. Fourthly, participants often felt vulnerable online as they had been the target of abusive and hateful messages. Participants were aware of some behaviours to look out for to keep themselves safe but sometimes spoke to people who they did not know online. Lastly, it was really important for participants to make their own decisions about how they used social media, but parents, carers and professionals often got involved when something 'bad' happened.

*Conclusion:* Social media was important in helping people with intellectual disabilities to feel like everyone else and their main reason for using it was to keep in touch with friends and family. There was reluctance on the part of the participants to talk about their use of the internet for sexual exploration and they mostly talked about negative experiences. More education is needed for both people with intellectual disabilities and for parents and professionals to allow people with intellectual disabilities to talk more openly about their use of the internet. This would hopefully help people to remain safe in their sexual explorations and with navigation of online platforms.

## **Abstract**

*Background:* Although the internet is a widely used tool for sexual exploration there is an absence of research concerning people with intellectual disabilities' use of the internet. This research investigates how young adults with intellectual disabilities use the internet for sexual exploration.

*Method:* Seven semi-structured interviews were conducted with young adults, aged 18 to 26, with mild-moderate intellectual disabilities. Interviews were analysed using reflexive thematic analysis.

*Results:* Five themes were generated: a) social media makes me feel connected, b) desire for intimacy c) porn is not for me d) I am vulnerable online e) who is in control?

*Conclusions:* Participants were mainly using the internet for social connection with some also seeking intimacy. There were negative views about some online sexual content, but it was hard for participants to explain why. There is a need for more education about internet use to increase opportunities for intimate connections.

*Key words:* intellectual disabilities, sexual exploration, qualitative, social media.

## **Introduction**

The internet has changed every aspect of daily life. One of the most significant changes is the way in which people develop and maintain relationships, with social media applications commonly used for connecting and communicating with others (Ofcom, 2022). Young adults in particular have the highest internet use of all age groups making it important to understand their experiences online (Office for National Statistics, 2022). The internet also has an increasingly important role in the creation of romantic relationships and has become a tool for sexual exploration (Chadwick et al., 2023b). Despite this change in the way in which people communicate and connect both platonically and romantically online, people with an intellectual disability continue to experience digital exclusion and disadvantage (Chadwick et al., 2023b).

An intellectual disability is defined as a condition that affects functioning in two core areas: cognitive functioning and adaptive functioning where an individual has difficulty or delay in development skills across these areas (American Psychiatric Association, 2024). This presents as difficulties with everyday tasks including with communication and speech, social interaction and play and learning and which begin in childhood (World Health Organisation, 2019). Due to the different terminology used in the area, it is difficult to ascertain the prevalence rates of people with an intellectual disability but the American Psychiatric Association (2024) estimates that around 1% of the global population are affected. In the UK, Public Health England (2016) estimate that there is approximately 2.16% of adults and 2.5% of children who have an intellectual disability. Research has found that the prevalence rates are two times higher in low and middle-income countries compared to high income countries demonstrating the variation in rates worldwide (Maulik et al., 2011). Intellectual disability is split into four categories: mild, moderate, severe and profound. Those with a more severe and profound intellectual

disability will require more support and assistance with certain areas (Mencap, 2024). There are many different causes of intellectual disability: research has shown that it is associated with genetic syndromes such as Down Syndrome or Fragile X syndrome, meningitis, whooping cough, measles, head trauma in childhood, exposure to toxins, complications during pregnancy and birth as well as with environmental factors such as alcohol or drugs during pregnancy (American Psychiatric Association, 2024; World Health Organisation, 2019). People with an intellectual disability often face stigma and barriers and social exclusion (Ali et al., 2012; Scoir & Werner, 2015).

There are significantly higher levels of loneliness reported in people with an intellectual disability and there are also significantly lower marriage rates-; 3% compared to 47% in the general population (Scottish Commission for People with Learning Disabilities, 2020). The internet has the potential to bridge this gap to help with building connections and promote inclusion (Sorbring et al., 2017). Furthermore, research has demonstrated that the internet has an important role in increasing knowledge, expanding social networks, meeting potential partners and exploring forms of sexual pleasure (Santinele Martino & Kinitz, 2022). The growth of the internet presents a unique platform for sexual exploration and there is a distinct lack of research on how people with an intellectual disability are experiencing the internet for this purpose (Santinele Martino & Kinitz, 2022). As more of people's lives are spent online, it is important to consider how this affects people with an intellectual disability and if they are having the same opportunities as those without a disability (Chadwick et al., 2023b). Research has demonstrated that this population are often socially excluded, and it is not known if this extends to the digital world. Previous literature has shown that digital skills are being taught to people with intellectual disabilities and the technology is being used to develop social connections, however much of this depends on the support the individual receives and an

emphasis is still being placed on offline connections (Chadwick et al., 2023b). There is currently limited research on how people with an intellectual disability are using the internet for sexual exploration.

Although there is less known about general internet use for individuals with intellectual disabilities, previous research has found that these individuals are less likely to use the internet compared to the general population (Borgström et al., 2019; Chadwick et al., 2013; Chadwick et al., 2017). There is now a growing evidence base involving people with intellectual disabilities' use of the internet, especially since the Covid-19 pandemic (Caton et al., 2023). This population use the internet to maintain connections with friends and family, for social and romantic reasons, to communicate with colleagues, as well as for travelling purposes (Danker et al., 2023; Ramsten et al., 2020).

People with an intellectual disability have historically faced multiple challenges when exploring sex and relationships which extends to the use of the internet for sexual exploration (Whittle & Butler, 2018). Even when individuals have smart phones or computers, the design and functionality of applications can make them difficult to use contributing to digital exclusion (Chadwick et al., 2023b). Moreover, the attitudes of those caring for this population can also limit people's access to the internet (Ågren et al., 2023; Caton et al., 2023; Chadwick et al., 2023a; Danker et al., 2023; Engwall, 2023; Seale, 2023). Previous literature has consistently found that parents and carers as well as support staff, may act as '*gatekeepers*' to people with an intellectual disability accessing the internet (Chadwick, 2019; Santinele Martino & Kinitz, 2022).

The experiences of people with an intellectual disability using the internet for sexual exploration has received limited research attention (Santinele Martino & Kinitz, 2022). Darragh et al. (2017) found that this population used social media and the internet to



connect with friends, arrange social events, engage with interest groups, but few were using it for exploring sexuality. Those that did were engaging with watching online pornography and participating in intimate relationships with people online. Sex education for adolescents and adults with an intellectual disability has not included online relationships and social media use, suggesting that this population have not received support to help them to use the internet for safe sexual exploration (Schaafsma et al., 2015). A more recent study found that there were multiple barriers for people with an intellectual disability when attempting to use the internet for sexual exploration; the cost of being online, navigating different dating apps, a lack of freedom to use technology independently, and not having the knowledge to navigate online platforms about sex and dating (Santinele Martino & Kinitz, 2022). There is a need for further research to better understand the experiences of this population using the internet for sexual exploration, to ensure that they have the opportunities to build romantic connections.

The risks around internet use for individuals with an intellectual disability have received more interest because this population is viewed as being vulnerable to online abuse and exploitation (Chiner et al., 2017; Chiner et al., 2022; Glencross et al., 2021). They have been blocked from online groups, insulted, threatened, sent unwanted sexual media and had their passwords used without their consent (Chiner et al., 2017). Cyberbullying and financial and sexual exploitation have also been reported to be more commonly experienced by people with an intellectual disability (Anderson et al., 2023). A further concern is that this population do not have the skills and knowledge to keep themselves safe, due to a lack of accessible sex and relationship education (Mencap, 2018). Darragh et al. (2017) found that older adults with intellectual disabilities were able to mitigate, assess and manage online risks. However, these skills were not learned from formal education. This is in contrast to research with young adults with intellectual disabilities

where it was found that although they were aware of personal safety risks, mitigations were not put in place online (Löfgren-Mårtenson, 2008). The fear about technology use is at odds with its uses to promote independence and connection and engagement with others (Ramsten et al., 2020). Finding out how young adults experience using the internet for sexual exploration could help educate both carers and professionals to help support this population to use the internet safely and to its fullest potential. Whilst there is a lack of research and evidence on internet use by people with an intellectual disability, young adults without a disability would appear to have the highest internet use rates, which makes this group the most important to research (Office for National Statistics, 2022).

The aim of this study is to investigate how young adults with a mild to moderate intellectual disability access the internet and their experiences of using the internet for sexual exploration.

### **Method**

The study followed the Consolidated Criteria for Reporting Qualitative Studies (CORE-Q, *appendix 2.1*) (Booth et al., 2014). The qualitative approach used in this study was reflexive thematic analysis (RTA) which was deemed the most appropriate due to its flexibility and broad scope. RTA allows the researcher to make sense of what is being said through developing, analysing and interpreting patterns across a qualitative database alongside a critical reflection of the role of the researcher and how this influences the analysis (Braun & Clarke, 2021). A critical realist approach was taken to the qualitative research; looking at the meaning around the topic and issue being addressed, while capturing the reality of participants experiences (Braun & Clarke, 2021).

#### *- Participants*

A voluntary response sampling method was used whereby potential participants attended in-person information sessions about the research and subsequently decided if they wanted to take part. In-person information sessions took place at three higher education colleges in the Scottish Highlands that provided courses for students with intellectual disabilities. These sessions were an opportunity for potential participants to hear about the research, the aims and why they were being asked to take part. The researcher did not know any of the participants prior to the interviews taking place. Participants met the following inclusion criteria: aged between 18 and 30, have a diagnosis of mild to moderate intellectual disability, able to communicate, understand and respond in English, and be able to give informed consent.

Seven young adults with mild-moderate intellectual disabilities (5 females, 1 male and 1 non-binary participant) were included in the final sample. The sample size is characteristic of qualitative research, where the focus is on data richness and quality (Braun & Clarke, 2021)

The participants' demographic details and pseudonyms are shown in *table 9*. All participants were aged between 18 and 26 ( $M=22.14$ ,  $SD=3.08$ ). Scores on the Wechsler Abbreviated Scale of Intelligence 2<sup>nd</sup> (Wechsler, 2011) ranged from 49 to 79 ( $M=61.86$ ,  $SD= 10.49$ ). All participants identified as white British. Due to the risk of identification and to protect the anonymity of participants, some information has not been linked to pseudonyms. One participant identified as pan-sexual, and one participant was receiving mental health support at the time of the interview. In addition to attending the college course, three participants were taking part in either employment or voluntary opportunities.

Table 9. Demographic information of the sample.

<b>Pseudonym</b>	<b>Age</b>	<b>Ethnicity</b>	<b>Living Situation</b>	<b>Relationship Status</b>	<b>WASI-II Score</b>
<b>Jessica</b>	18	White British	Home	Current	79
<b>Sarah</b>	20	White British	Home	Previous	65
<b>Emma</b>	20	White British	College	Previous	62
<b>Daniel</b>	26	White British	College	No	53
<b>Jenny</b>	22	White British	College	Previous	49
<b>Alex</b>	23	White British	College	Previous	70
<b>Kate</b>	26	White British	College	Previous	55

- *Interview and measures*

*Socio-demographic information:* Age, gender, sexuality, ethnicity, relationship status, living situation and if participants were receiving any mental health support was collected from participants (*appendix 2.5*).

*Interview:* The interviews were semi-structured allowing for the same questions to be used and for flexibility in responding and reacting to answers. It was important during the interviews to put participants at their ease and to create a more discursive space when exploring the topics, whilst being vigilant to avoid asking leading questions. The first part of the interview focused on closed questions regarding internet use and the devices used. The aim of this was to provide contextual information about internet access.

The second part of the interview was a social media app logo quiz (*appendix 2.6*) designed for this study to help facilitate discussion around different apps. The aim was to help put participants at their ease discussing a personal topic. Apps included were:

BeReal, Bumble, Facebook, Grindr, Instagram, Porn Hub, Reddit, Snapchat, TikTok, Telegram, Twitter (X), Messenger and Yubo. These were chosen based on clinical experience working with young adults with intellectual disabilities and obtaining information about the apps that were most frequently used (You Gov, 2024). The dating apps, Tinder, Bumble and Grindr were chosen to introduce topics around online dating and sexual exploration. Grindr specifically was chosen due to its reach for the LGBTQ+ community. Porn Hub was included to help open discussions about online pornography as this was reported as being viewed by participants with intellectual disabilities in previous studies (Darragh et al., 2017; Santinele Martino & Kinitz, 2022). Participants also had opportunities to talk about other apps.

The third part of the interview were open-ended questions about internet use for sexual exploration and a discussion about other topics which may have come up during the interview. A topic guide was created for the interviews based on the research aims around exploring how the internet was being used to find out about sex and relationships. This guide was informed by previous research by Darragh et al. (2017). It was important that the questions were accessible and open to enable participants to understand and be able to respond. Both the research and field supervisors who have worked and researched with people with an intellectual disability provided extensive feedback on the question wording. The lead researcher also used their clinical knowledge and experienced on how to make questions accessible. As there is a variation in level of understanding, communication and processing abilities for people with an intellectual disability. Therefore, it was important to create a topic guide to help ensure particular subjects were covered while providing flexibility to adapt it to the particular concerns and communication style of the participant. The guide (*appendix 2.7*) focused on questions about participants' use of the internet to find a romantic partner, how they found things

out about sex and relationships, content participants had seen on apps related to sex and relationships and questions about online sexual content. These areas formed the subject headings of the interview. The topic guide was trialled with the first two participants, following which two additional questions were added. These questions specifically asked participants about how they would find something out about sex and relationships (as highlighted in *appendix 2.7*).

*Wechsler Abbreviated Scale of Intelligence (WASI-II; (Wechsler, 2011)*: The WASI-II is an abbreviated version of the Wechsler Adult intelligence Scale (WAIS-III) and was completed at the end of the interview. It was used as an estimated measure of cognitive ability to provide contextual information about the participants. The two-subscale version (FSIQ-2) was chosen for the current study. Correlations between the WASI-II and WAIS-III are acceptable (*Vocabulary = 0.88; Matrix Reasoning = 0.66; Overall = 0.87*).

#### - *Procedure*

Study materials (*appendix 2.8-2.10*) were reviewed and informed consent was obtained prior to starting the interviews, which took place at the education setting that participants were recruited from. Only the lead researcher and participant were present, and the average length was 57 minutes. Participants were given the option of having their interview recorded and all but one participant consented to this. Extensive notes were taken during this one interview and coded as part of the data analysis.

On completion of the semi-structured interview, participants completed the vocabulary and matrix reasoning subtests of the WASI-II. A debrief form (*appendix 2.11*) was provided and discussed and participants received a £10 amazon voucher.

#### - *Data Analysis*

RTA is an inherently flexible and iterative process in that researchers do not proceed using a linear method during the six phases of analysis (Braun & Clarke, 2021). To begin with, interviews were transcribed verbatim using Microsoft Word and transferred to NVivo (Lumivero, 2023) for analysis. The first phase, *familiarisation*, involved reading and re-reading the transcripts and listening to the audio files becoming immersed in the data. Brief notes about insights or analytic ideas were recorded. The second phase, *coding*, involved working systematically through the transcripts for meaningful and interesting segments and applying labels to them, thereby capturing an analytical take on the data. The third phase, *generation of initial themes*, involved identifying patterns from the codes across the dataset and looking for codes that share core ideas. Through discussion with the research supervisor, it emerged that the initial themes were too descriptive and only summarised the topic areas within the interviews. Following this, the coding phase was revisited. During phase four, *developing and reviewing themes*, themes were checked against the transcripts to ensure that they made sense. Phase five, *refining, defining and naming themes*, involved ensuring that each theme had a core construct underlying it and that there was a clear message from each theme. One theme was refined and redefined to ensure that the core construct was clear and understood. Phase six, *writing up*, used reflective notes, familiarisation notes and the data extracts to write a narrative that addresses the research aim.

To ensure that data was analysed in a robust and transparent manner, checks, discussions with research supervisors and systematically recording the decisions that were made with regards to coding and the development of themes was carried out.

- *Researcher reflexivity*

As highlighted in Braun and Clarke (2021) a central part of RTA is for the researcher to reflect on their own experience and beliefs, and consider how this influences their

interpretation of the data. The researcher is a trainee clinical psychologist with experience of working therapeutically with young adults with intellectual disabilities who were having difficulties online and with their social relationships. The lead researcher has previous experience of interviewing vulnerable participants as well as leading interviews on sensitive and personal material. In their clinical role, the researcher has experience of talking openly about sex and intimate relationships with clients. However, in a research field with no previous therapeutic relationship with the participants, this may have contributed to feelings of awkwardness during the interviews. As well as these reflections, it was also important to consider the lead researcher's age and phase of life during the interview and the influence of this on participants and theme generation. The lead researcher is in their early 30's which could have contributed to participants feeling more or less safe to share during interviews. It may have been easier for participants who were broadly in their 20s to speak with someone who was closer in age to them. However, it could also have contributed to socially desirable answers been given as participants may have felt that they were expected to have a particular opinion about the internet and sexual exploration. The researcher identified that she viewed the internet as a place of positive opportunity for all, and that this was having an impact on emergent themes. This was documented in the reflective notes which she kept during the analysis.

- *Ethical considerations*

The University of Glasgow's College of Medical, Veterinary and Life Sciences Ethics Committee granted approval for this study (*Project number: 200220418*). Particular consideration was given due to the sensitive nature of the topic, the vulnerability of participants taking part and providing accessible materials. For the researcher, considering the process of disclosure during interviews and the next steps for this was important. The content shared in the interview was about online experiences which could



have involved experiences of abuse, exploitation or criminal activity online. Therefore, a key part of the consent process was explaining to participants that what they said would not be shared unless there was significant concern about risk of harm to themselves or to someone else.

## **Results**

The results section is split into two parts: i) the findings about the participants' device and app use, and ii) the themes generated from the semi-structured interviews.

### **Device and App Use**

Six of the seven participants owned a phone at the time of interview. One participant (*Sarah*) had recently had their phone removed by their parents due to concerns about online safety. Three participants owned a tablet which was for gaming and three also had their own laptop. Emma had also recently had their laptop removed by their carers due to concerns about online safety. Five participants owned a Nintendo Switch which was used for gaming.

*Figure 2* shows that the most common apps used (or previously used) by the participants were WhatsApp, TikTok and Facebook Messenger, Telegram, BeReal and Reddit. No participants reported using any of the dating apps included (Tinder, Bumble or Grindr) and no participants recognised or were using Yubo (a social media messaging app).

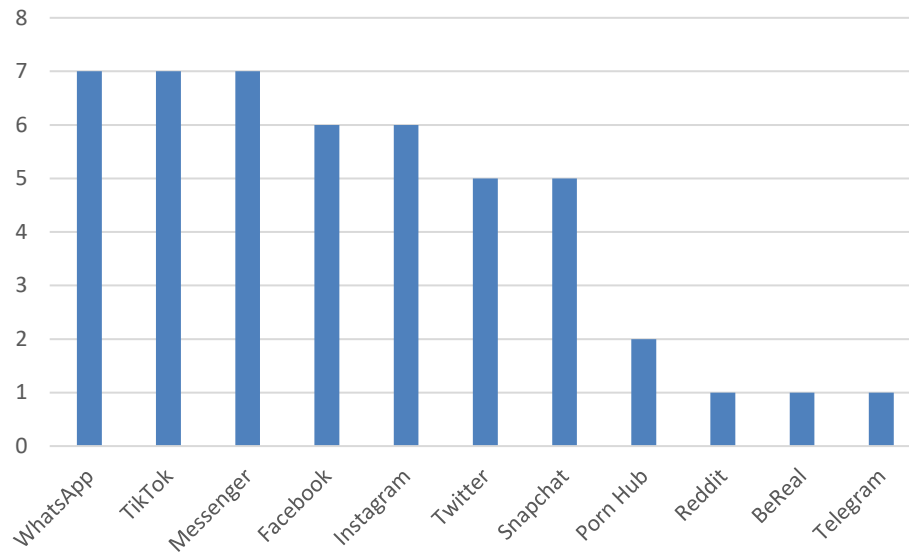


Figure 2. Social media apps most used by participants.

### Themes from semi-structured interviews

Five themes and two sub-themes, shown in *table 10*, emerged from the analysis. Participants appeared reluctant to talk about sex and dating, therefore the data and subsequent themes reflected their experiences of social media more widely. The themes are described then illustrated with quotes from participants with any identifiable features removed from transcripts.

Table 10. Themes and sub-themes generated from participant interviews.

	<b>Themes and Sub-themes</b>
<b>What are the experiences of young adults with mild-moderate intellectual disability of using the internet for sexual exploration?</b>	1. Social media makes me feel connected
	2. Desire for intimacy
	3. Porn is not for me
	4. I am vulnerable online <ul style="list-style-type: none"> <li>a. An unsafe place</li> <li>b. Red flags</li> </ul>
	5. Who is in control?

- Theme 1: Social media makes me feel connected

Social connection was seen as an important reason for using social media. Participants talked about social media as being a way of keeping in touch with friends and family and how the apps promoted a sense of belonging and reciprocity. There was a sense of shared experiences and how much participants valued social media as a tool for strengthening friendships.

*“Just in general, I like it to communicate to people and see what they’re doing and stuff” (Kate)*

*“Just sometimes post stuff, just what I’ve been up to” (Jenny)*

Participants felt that social media created a sense of community with other people online further increasing the sense of connection. This suggests that social media is a place where participants are able to do the same things as everyone else and participate in a reciprocal exchange of interests. Participants felt that they learned about other people’s lives and gained other knowledge through the shared experience of social media and this felt important to participants with an intellectual disability who do not have the same social opportunities as people without an intellectual disability.

*“Like, when it comes to good, good people. And I like the posts as well. I like the stories they put up. Cause you know, it’s interesting and finding out about life and all that.” (Jessica)*

Participants also felt that social media helped them to build new friendships online, with people from around the world.

*“I might get messages from people all around the world on WhatsApp.” (Daniel)*

*“Well, I know some of them, but I have made friends or like people from other countries” (Alex)*

This gave participants the sense that they were expanding their social circle and experiencing the internet like everyone else.

- *Theme 2: A desire for intimacy*

Despite many participants avoiding the topic of sex itself, participants expressed an interest in romantic relationships and building intimacy with others. Participants spoke about using social media to connect with others in order to find a romantic partner. There was a general awkwardness in participants when being asked about content related to sex; with closed answers and giggling. There was a notable difference to their more open answer to other questions about relationships. A number of reasons could have contributed to this; participants may have felt awkward talking about sex with someone they did not know; they may have wanted to answer in a socially desirable way or may have not have had an interested in sex. However, social media was being used by some to build relationships with a goal of achieving sexual intimacy. This was especially true for Alex and Daniel who had previously looked for intimate partners online, wanting these to go further than platonic friendships.

*“Interviewer: Yeah, and do you talk to them a bit about relationships and sex?”*

*Daniel: Not yet, not yet, but it is the hope” (Daniel)*

Participants seemed to hope that because social media was a useful tool for connecting with other people with shared interests it would help them to find an intimate partner. However, the participants’ found it difficult to build intimacy with people they met online because they were often living in different places. Ultimately, they wanted to have a

relationship with someone they could meet in person. To this end, Daniel wanted to start using dating apps.

*“I really want to meet real people who do that stuff and who actually live in this country to appear on my profile” (Daniel)*

However, some of the participants did not feel that dating apps would help them meet a potential sexual partner in person.

*“I’d rather date someone that I’ve met” (Alex)*

*“[talking about dating apps] I personally find them pointless... meanwhile you can just go and talk to someone in the street” (Jessica)*

Participants also described the internet as a tool for finding things out about intimacy. Few admitted to looking for sexual or relationship content but did say that they would engage with this content if they came across videos or posts giving sex, relationship or dating advice. Sarah had watched videos on relationship advice and found this helpful.

This demonstrates that although there was a desire for intimacy, it is important to recognise that what was being searched for was different across the participant group. Whereas some participants spoke about seeking out a sexual relationship, other participants desire for intimacy was on a more emotional level. This may suggest that participants are exploring their sexuality on their own terms, although it may also be indicative of limited knowledge and skills around relationships.

- *Theme 3: Porn is not for me*

Participants appeared to express a distinct view that pornography was not for them. When the topic was raised by the researcher with participants it was usually shut down immediately. Participants were quick to offer their opinions about watching pornography

and about other people who watch it and were often not open to discussing this further. There was a sense that they felt embarrassed talking about pornography and felt that it was not suitable to watch.

*“I would never use, never will...because I don’t like watching, I never watch porn, Like I don’t want to know about it” (Emma)*

*“Then I’m like yeah no. I don’t want to, feels wrong, like too much for it...never again” (Jessica)*

When Daniel was asked about why pornography was not for him, he found it difficult to answer but was clear that if he found out one of his friends was watching pornography, he would *“just disconnect them” (Daniel)*. Emma suggested that she thought that boys mostly watch pornography, and she was not sure who else watched it. It appeared that most participants had not watched porn and that they found it an embarrassing and uncomfortable topic to discuss. It was difficult for other participants to put into words why they thought pornography was not okay. This might have been because their rejection of pornography reflected others’ views or a general sense of embarrassment rather than a complete lack of knowledge. This could also be explained by participants wanting to answer in a socially desirable way or not feeling comfortable when asked about watching porn. When asked why other people watched pornography, Emma said it was *“for the sex” (Emma)*, whereas Jessica talked about how it might be an educational tool for some people.

*“I mean it could, erm, it can be a learning experience for people sometimes. Like if someone was curious, and they can go on there and yeah see how things work”*

*(Jessica)*

This demonstrated that participants did know what pornography was. However, there was a sense that the participants did not believe that pornography was suitable for people with intellectual disabilities and that even talking about it was not okay.

- *Theme 4: I am vulnerable online*

This theme is split into two subthemes: an unsafe place and red flags. These subthemes reflect the upsetting and worrying online experiences that participants described.

o *An unsafe place*

Participants reported experiencing a high level of cyberbullying online. Kate had been cyber-bullied by someone she knew in-person, and Daniel had had his Facebook profile hacked numerous times and also had negative comments directed towards him. It appeared from the interviews that the internet was being used as a tool for directing hate and abuse towards others. Alex also described receiving negative comments from other people.

*“I had her pretending, messaging me on her account, and making up names...and just the words that she was saying... just nasty names and stuff. Nasty comments” (Kate)*

It appeared that participants found the internet unsafe and had become wary of other people online. This contributed to feelings of loneliness and rejection. While these experiences may not be unique to people with an intellectual disability, belonging to a socially marginalised group may have exacerbated the impact of online bullying and rejection. Participants were also aware that people online were not always who they said they were and participants were wary about being scammed.

*“Because it’s a dating app and you might come across a person you might like but that might not actually be them. It could be someone pretending or role-playing or whatever*

*and it could be like, say a young man, and it's actually technically an old woman"*

*(Alex)*

Daniel had reduced his social media use as he was not confident about managing these situations.

- *Red Flags*

Participants were able to identify “*red flags*” (*Jessica*), looking out for suspicious behaviour online. Participants described looking at people’s pictures to determine who they might be and if they wanted to speak to them. Kate was aware that the pictures used may be fake.

*“a few people say they’re like Henry Cavill and stuff...it’s not like him at all, like a picture of an African man talking on the phone” (Kate)*

Jessica also expressed a concern about the words people used online, and this helped her know if someone was being a “*creep*” (*Jessica*).

*“If they friend you and they kind of message you like hii sweetie, that means that’s a red flag...it’s just the way they text” (Jessica)*

Participants also talked about negative experiences when using social media for sexual exploration. A common experience was being sent naked images. Participants expressed worry and concern about how to deal with these experiences.

*“There was this one person when I was 13 and I believe he was in his 20s...he started to message me on Instagram....start to post snap pictures and I got worried that he would get closer, like something more...my friend was like hey maybe you should block and delete and that’s what I did, just in case it got like further” (Jessica)*



Jessica had been worried that the pictures she was being sent would get progressively more explicit. Sarah and Emma had also received naked images from people online. Once again, these experiences will not be unique to people with intellectual disabilities, but how they are understood and conceptualised by this group may be different, particularly if they have more limited confiding relationships and fewer people to seek support from.

While these accounts suggest that participants often felt vulnerable and unsafe online this did not always appear to result in greater caution. Participants talked about making friends on the internet and described these as “*best friends*” (Jessica). This could suggest that if people online did not display specific *red flags*, it may be that participants would make a judgement that they were safe people.

- *Theme 5: Who is in control?*

Across all interviews, it appeared that participants were confident making choices about who they spoke to online and how they were using the internet. Emma for example was very clear- “*I know the things I like and the things I don’t like*” (Emma). It was also clear that participants were able to keep themselves safe and knew how to block and report someone online thus demonstrating that participants had learned some protective abilities and skills. However, they were still feeling vulnerable online as evidenced in theme four. Participants used the private and public function of social media apps to control other people’s access to their profiles.

*“Just you can block people, if necessary, decline a request, or report them if something happens” (Alex)*

*“Like I want to go public, I’ll go public. When I go private, I’ll go private” (Daniel)*

This may suggest that either through experience or education, participants knew how to keep themselves safe online and that independent decision making was important. There was a sense that participants were exploring their own boundaries online and these differed across the group.

However, this sense of control appeared fragile and illusory at times. Participants reported that parents and carers would step in when difficulties occurred, and they were often left feeling confused and at fault for what happened. Sarah said that her phone and laptop had been removed by her parents after they found out that she had been sharing naked images with someone else, with similar incidents described by Emma and Kate. In Emma's case, the police became involved. Kate did not seem to understand why her laptop had been removed and was unsure when she would be getting it back.

*“So, I don't really know why my laptop was taken off me” (Kate)*

Sarah felt that her parents did not trust her after this experience and Emma said she felt scared and at fault because of the police investigation. Participants talked about how hard it was when other people became involved. This suggests that other people's responses to these situations are important. It appeared that the participants knew their online independence was conditional and that ultimate control rested with others.

## **Discussion**

This study investigated use of the internet for sexual exploration by young adults with mild to moderate intellectual disability. The themes from this research were; *social media makes me feel connected, a desire for intimacy, porn is not for me, I am vulnerable online and who is in control*. During the interviews, the topic of sexual exploration was difficult for participants to talk about. This could be explained by sex remaining a taboo topic and

discussed with apprehension (Gourlay, 2024). However, participants were willing to discuss their relationships and disclose negative personal experiences.

In line with prior research (Barlott et al., 2020; Danker et al., 2023; Ramsten et al., 2020), this study found that social media was being used by the participants to keep up to date with their friends and family, post their own updates and play online games using a variety of devices. Only a minority of participants in this study talked about using the internet for sexual exploration with some participants actively searching for an intimate relationship. This supports previous research which has found that people with intellectual disabilities wish for a sexual relationship (Hole et al., 2022). The study also found that some participants had shared explicit images online, which can be seen as a way of exploring their sexuality. Sharing sexual images has been found to be normative sexual behaviour with young adults, with a common reason being to flirt or finding it sexually arousing (Thorne et al., 2024). There is an absence of research about sharing sexual images by people with an intellectual disability, but as part of a wider study on sexual knowledge, this population were found to have a lack of knowledge about sharing sexual images (Estruch-García et al., 2024). Relationship and sex education should take account of this and provide education on safe practices for online sexual exploration (Estruch-García et al., 2024; Thorne et al., 2024).

In contrast to the findings from Darragh et al. (2017), participants in this study held strong opinions that watching online pornography was unacceptable. As evidenced in previous research participants may have been repeating negative messages that they had heard from parents, carers and support staff (Darragh et al., 2017). There is limited evidence about the use of pornography with people who have an intellectual disability but studies with the general population have reported high usage across all age groups (Ballester-Arnal et al., 2023). Therefore, it is surprising that the participants reported that they were

not engaging with the content. Relationship and sex education for people with an intellectual disability has also tended to exclude references to online pornography, which may also explain why the participants in this study relied on messages from parents or support workers (Schaafsma et al., 2015).

The participants spoke about negative online experiences; from receiving abusive content to being sent inappropriate or uncomfortable messages. This is consistent with findings by Chiner et al. (2017), who found that people with intellectual disabilities received unwanted sexual content, abusive language or were blocked from online groups. In common with research in this area, participants also talked about being bullied online or being sexually or financially exploited (Holmes & O'Loughlin, 2014). However, the online experiences of people with intellectual disabilities are not unlike the experiences of young adults without a disability. A rapid review conducted in 2019 found that the numbers of young adults, experiencing online harassment (including sexual) and cyberbullying were increasing and having a significant long-term impact (Davidson et al., 2019). Hence, there is a need for more research on how these experiences are understood by people with an intellectual disability and ensuring that they have the relevant education and support to help them navigate and cope with these challenges.

Participants valued making their own decisions about their use of social media, highlighting the importance of choice and control. These results reflect previous research, where the use of digital media increased independence and autonomy in daily life (Barlott et al., 2020; Ramsten et al., 2020). Participants were also able to make decisions on how to keep themselves safe online. Interestingly, Darragh et al. (2017) found that adults with an intellectual disability were able to identify risks as well as being able to problem-solve to navigate these risks. This research found that although participants were able to identify problem behaviours online and had some skills and abilities in navigating them,

this did not stop them from engaging in risky online behaviour. Previous research suggests that even though younger adults can identify online risks, it did not necessarily change their behaviour (Löfgren-Mårtenson, 2008). It is notable that the participants in this study were young adults, who have a tendency to engage in more risky behaviours online (White et al., 2015).

The roles of parents, carers and other professionals were highlighted during the interviews. Participants reported that parents and staff would get involved when they had exchanged sexually explicit images. The response was often to remove their devices. Similar findings were found by Darragh et al. (2017) and Santinele Martino and Kinitz (2022). The idea of parents and carers gatekeeping by controlling and restricting access has been found in previous research (Chadwick, 2019). The context of sharing intimate images needs to be taken into account when deciding upon a response and attributing blame (Temple et al., 2019). Education for those supporting people with intellectual disabilities could help to promote open conversations about safe online behaviour, an idea supported by more recent research by Gil-Llario et al. (2023).

- *Study limitations*

There were a number of limitations to the current study. Firstly, fewer participants took part in the study than planned. Whilst there is no required sample size for RTA, data quality needs to be considered (Braun & Clarke, 2021). The quality of the data obtained in the interviews varied between participants. One participant, in particular, was reluctant to talk in detail about their experiences which would have influenced the data quality overall. Recruitment also proved difficult. A key problem was gaining access to potential participants to provide information about the project, as staff had to agree to hold an information session. There was a reluctance from some organisations that were approached due to the subject nature of the research. It is well established that conducting

research with people with an intellectual disability can be challenging due to organisational barriers, such as gaining approval from managers, staff feeling that it is their place to make decisions on the part of potential participants and ethical considerations. These challenges are more complex when researching a sensitive topic (Crook et al., 2016; Harding, 2021; National Institute for Health Research, 2020).

Another limitation was that the inclusion criteria required participants to be able to consent in their own right. Consequently, participants who were on welfare guardianship orders who required agreement from their guardians were excluded. These individuals may have less access to the internet and future research should explore their experiences and views (Santinele Martino & Kinitz, 2022). The method used in this research excludes people with more severe and profound intellectual disability as they would be unable to take part in semi-structured interviews. Future research should consider the use of other approaches, such as talking mats to explore this groups views and experiences of using the internet.

To facilitate discussion during the interview, a social media app logo quiz was developed to put participants at their ease. This resulted in large parts of the interview discussing the pros and cons of particular social media apps, and less on how these apps were being used for sexual exploration. The benefit of building a rapport was that participants were relaxed enough to share experiences but may have diverted attention away from the use of the internet for sexual exploration. Further to this limitation, the questions used in the topic guide did not go through a process of co-production with members from the study population. This could have helped to determine the content covered, the questions asked and the language used. However, the lead researcher consulted both research and field supervisors on the project who have extensive experience of working both in research and clinically with this population.

Finally, the researcher's own position may have influenced the information shared during the interviews and the themes generated from them. As discussed in the methods section, the researcher was a female researcher and there was not a significant difference in age between some participants and the researcher. This could have led to participants answering in a socially desirable way, but also could have contributed to participants feeling comfortable to share their experiences. Participants may have felt that they were expected to answer in a particular way or wanted to appear socially desirable in front of a researcher whose was close in age to them. Additionally, this study was conducted in the Scottish Highlands with participants from two organisations. While there were some differences between the participants, they were largely homogenous in terms of ethnicity, gender, and living situation. Future research should capture the voices of a broader range of participant backgrounds to obtain a broader range of perspectives.

- *Strengths*

The current study had a number of strengths and added to the field of research about our understanding of how the internet and social media is being used by people with a mild to moderate intellectual disability to build both platonic and intimate relationships. It gave a voice to a group of individuals whose views and opinions are often disregarded or unheard due to the complexities of including this population in research (Chadwick et al., 2023b). Previous research has often included the views and experiences of parents and carers of this population, but by focusing on the individuals themselves and their own experiences, it has provided a personal perspective. By including this perspective, the research indicates that people were reluctant to talk about sex in detail, nonetheless, it suggests that this population are using the internet for the creation and maintenance of both platonic and intimate relationships.

The current study also developed a novel way of engaging participants with a mild to moderate intellectual disability in research interviews. By creating a social media app logo quiz, this opened up the conversation about different social media apps and provided a focus during the interviews. This approach took account of individual differences in the participants' understanding and communication, thereby scaffolding their involvement in the research.

- *Implications*

There are a range of implications that can be drawn from the results of this work. This study has highlighted the important role that social media and the internet plays in the creation, development and maintenance of social connections both platonic and romantic for people with a mild to moderate intellectual disability. The internet has changed many aspects of daily life and the results indicate that this is also the case for people with intellectual disabilities. Clinically, it is vital that professionals working in the area work with this client group to provide education to help them navigate the internet safely. This study suggests that when restrictive measures were used, such as the removal of devices, there was a range of emotions felt by the individual. It is important for clinicians and wider professionals to be aware of the impact of more restrictive measures, in order to be able to provide appropriate support. The current study has also highlighted areas for future research. Making sense of the experiences that this population have online, particularly around harassment and cyberbullying would be helpful in order to create safe online spaces. There is also limited research exploring pornography use by this population, which should be explored further. More widely, there is a need to provide more comprehensive relationship and sex education which focuses on online behaviour and spaces as well as on online pornography.



- *Conclusion*

This study adds to a growing evidence base about internet use and its opportunities for sexual exploration by people with an intellectual disability. It has highlighted that the internet can be used as a tool for this group seeking intimacy. This study has shown that while people with intellectual disabilities can recognise risky behaviour, this does not necessarily result in a behaviour change. It highlights the need for further research about people with learning disabilities' understanding of the online world. There is also a need for sex and relationship education to take account of their online experience. Moreover, the findings show that parents, carers and professionals also need help, as they play a key role in supporting people with an intellectual disability. As our online and offline worlds merge, it is crucial that people with intellectual disabilities are able to take advantage of digital opportunities.

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## Appendices

### Appendix 1: Systematic Review

#### Appendix 1.1: PRISMA Checklist

Section and Topic	Item #	Checklist item	Location where item is reported
<b>TITLE</b>			
Title	1	Identify the report as a systematic review.	Title
<b>ABSTRACT</b>			
Abstract	2	See the PRISMA 2020 for Abstracts checklist.	Abstract
<b>INTRODUCTION</b>			
Rationale	3	Describe the rationale for the review in the context of existing knowledge.	Intro. Page 14.
Objectives	4	Provide an explicit statement of the objective(s) or question(s) the review addresses.	Intro. Page 14.
<b>METHODS</b>			
Eligibility criteria	5	Specify the inclusion and exclusion criteria for the review and how studies were grouped for the syntheses.	Method Page. 15-16.
Information sources	6	Specify all databases, registers, websites, organisations, reference lists and other sources searched or consulted to identify studies. Specify the date when each source was last searched or consulted.	Method Page. 15-16.
Search strategy	7	Present the full search strategies for all databases, registers and websites, including any filters and limits used.	Method Page 15 Appendix 1.2
Selection process	8	Specify the methods used to decide whether a study met the inclusion criteria of the review, including how many reviewers screened each record and each report retrieved, whether they worked independently, and if applicable, details of automation tools used in the process.	Method Page. 16-18.
Data collection process	9	Specify the methods used to collect data from reports, including how many reviewers collected data from each report, whether they worked independently, any processes for obtaining or confirming data from study investigators, and if applicable, details of automation tools used in the process.	Method Page. 17-18.
Data items	10a	List and define all outcomes for which data were sought. Specify whether all results that were compatible with each outcome domain in each study were sought (e.g. for all measures, time points, analyses), and if not, the methods used to decide which results to collect.	Method Page. 18.
	10b	List and define all other variables for which data were sought (e.g. participant and intervention characteristics, funding sources). Describe any assumptions made about any missing or unclear information.	Method Page. 18.
Study risk of bias assessment	11	Specify the methods used to assess risk of bias in the included studies, including details of the tool(s) used, how many reviewers assessed each study and whether they worked independently, and if applicable, details of automation tools used in the process.	Method Page. 18.
Effect measures	12	Specify for each outcome the effect measure(s) (e.g. risk ratio, mean difference) used in the synthesis or presentation of results.	N/A
Synthesis	13a	Describe the processes used to decide which studies were eligible for each synthesis (e.g. tabulating the study intervention	Method



Section and Topic	Item #	Checklist item	Location where item is reported
methods		characteristics and comparing against the planned groups for each synthesis (item #5)).	Page 19.
	13b	Describe any methods required to prepare the data for presentation or synthesis, such as handling of missing summary statistics, or data conversions.	N/A
	13c	Describe any methods used to tabulate or visually display results of individual studies and syntheses.	Method Page. 19.
	13d	Describe any methods used to synthesize results and provide a rationale for the choice(s). If meta-analysis was performed, describe the model(s), method(s) to identify the presence and extent of statistical heterogeneity, and software package(s) used.	Method Page. 19
	13e	Describe any methods used to explore possible causes of heterogeneity among study results (e.g. subgroup analysis, meta-regression).	N/A
	13f	Describe any sensitivity analyses conducted to assess robustness of the synthesized results.	N/A
Reporting bias assessment	14	Describe any methods used to assess risk of bias due to missing results in a synthesis (arising from reporting biases).	N/A
Certainty assessment	15	Describe any methods used to assess certainty (or confidence) in the body of evidence for an outcome.	Method Page. 18.
<b>RESULTS</b>			
Study selection	16a	Describe the results of the search and selection process, from the number of records identified in the search to the number of studies included in the review, ideally using a flow diagram.	Results Page. 19-20.
	16b	Cite studies that might appear to meet the inclusion criteria, but which were excluded, and explain why they were excluded.	Results Page. 19-20.
Study characteristics	17	Cite each included study and present its characteristics.	Results Page. 21-22.
Risk of bias in studies	18	Present assessments of risk of bias for each included study.	Results Page. 22-25
Results of individual studies	19	For all outcomes, present, for each study: (a) summary statistics for each group (where appropriate) and (b) an effect estimate and its precision (e.g. confidence/credible interval), ideally using structured tables or plots.	Results Page. 34-44.
Results of syntheses	20a	For each synthesis, briefly summarise the characteristics and risk of bias among contributing studies.	Results Page. 34-44.
	20b	Present results of all statistical syntheses conducted. If meta-analysis was done, present for each the summary estimate and its precision (e.g. confidence/credible interval) and measures of statistical heterogeneity. If comparing groups, describe the direction of the effect.	Results Page. 34-44.
	20c	Present results of all investigations of possible causes of heterogeneity among study results.	Results Page. 24-44
	20d	Present results of all sensitivity analyses conducted to assess the robustness of the synthesized results.	N/A
Reporting	21	Present assessments of risk of bias due to missing results (arising	N/A

Section and Topic	Item #	Checklist item	Location where item is reported
biases		from reporting biases) for each synthesis assessed.	
Certainty of evidence	22	Present assessments of certainty (or confidence) in the body of evidence for each outcome assessed.	Results Page. 34-44.
<b>DISCUSSION</b>			
Discussion	23a	Provide a general interpretation of the results in the context of other evidence.	Discussion Page 45-49.
	23b	Discuss any limitations of the evidence included in the review.	Discussion Page. 47.
	23c	Discuss any limitations of the review processes used.	Discussion Page. 47.
	23d	Discuss implications of the results for practice, policy, and future research.	Discussion Page. 48-49.
<b>OTHER INFORMATION</b>			
Registration and protocol	24a	Provide registration information for the review, including register name and registration number, or state that the review was not registered.	Method Page. 15.
	24b	Indicate where the review protocol can be accessed, or state that a protocol was not prepared.	N/A
	24c	Describe and explain any amendments to information provided at registration or in the protocol.	N/A
Support	25	Describe sources of financial or non-financial support for the review, and the role of the funders or sponsors in the review.	N/A
Competing interests	26	Declare any competing interests of review authors.	N/A
Availability of data, code and other materials	27	Report which of the following are publicly available and where they can be found: template data collection forms; data extracted from included studies; data used for all analyses; analytic code; any other materials used in the review.	N/A

From:

Page, M. J., McKenzie, J. E., Bossuyt, P. M., Boutron, I., Hoffmann, T. C., Mulrow, C. D.,

Shamseer, L., Tetzlaff, J. M., Akl, E. A., Brennan, S. E., Chou, R., Glanville, J.,

Grimshaw, J. M., Hróbjartsson, A., Lalu, M. M., Li, T., Loder, E. W., Mayo-Wilson, E.,

McDonald, S., . . . Moher, D. (2021). The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. *BMJ*, 372, n71.

<https://doi.org/10.1136/bmj.n71>

Appendix 1.2: Database Search Terms

**PsycINFO Search Terms 220324**

#	Query	Results from 22 Mar 2024
1	exp Learning Disabilities/	29,736
2	exp Learning Disorders/	36,707
3	exp Special Education Students/	9,560
4	exp Developmental Disabilities/	16,448
5	exp Intellectual Development Disorder/	50,024
6	exp Autism Spectrum Disorders/	57,834
7	exp Down's Syndrome/	7,084
8	exp Rett Syndrome/	998
9	exp Prader Willi Syndrome/	620
10	exp Fragile X Syndrome/	2,098
11	exp Crying Cat Syndrome/	76
12	exp Cornelia De Lange Syndrome/	53
13	1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12	158,352
14	(learning disab* or learning difficult* or learning disorder or learning impair* or intellectual* disab* or intellectual* impair* or intellectual dysfunction or development* disab* or development* disorder* or development* impair* or intellectual developmental disorder or mental* deficien* or mental* retard* or mental* handicap* or mental* disab* or mental insufficiency or mental* impair* or mental* challenged or IQ or subaverage intelligence or cognitive impair*).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures, mesh word]	216,732

15	(autis* or Asperg* or Down Syndrome or trisomy 21 or Smith-Magenis or Rett* or Lesch-Nyhan or Prader-Willi or Angelman or fragile X or Cri-du-chat or Cornelia de Lange or de Lange or Rubinstein-Taybi).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures, mesh word]	83,322
16	(special education* or special need* or additional support* or additional need*).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures, mesh word]	57,167
17	14 or 15 or 16	311,948
18	13 or 17	323,469
19	exp Sex/	131,548
20	exp Sexuality/	18,824
21	exp Psychosexual Behavior/	265,123
22	exp Sexual Development/	1,873
23	exp Sexual Health/	3,730
24	19 or 20 or 21 or 22 or 23	273,849
25	(sex or sexuality or psychosexual behavior or sexual development or sexual health or psychosexual development or sexual behavior or psychosexual health).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures, mesh word]	401,251
26	24 or 25	463,154
27	exp Education/	505,094
28	exp Educational Programs/	70,815

29	exp Training/	95,602
30	exp Curriculum/	136,122
31	27 or 28 or 29 or 30	553,432
32	(education or training or curriculum or program*).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures, mesh word]	1,145,072
33	31 or 32	1,232,109
34	26 and 33	94,295
35	exp Sex Education/	4,295
36	(sex education or relationship* education).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures, mesh word]	10,056
37	34 or 35 or 36	94,839
38	18 and 37	6,346
39	Limit 38 to (English and journal article)	4,673

#### **Medline Search Terms 21.03.24**

	<b>Query</b>	<b>Results from 23 Mar 2024</b>
1	Intellectual Disability/	60,714
2	Learning Disabilities/	14,722
3	Developmental Disabilities/	22,584
4	Education, Special/	9,110

5	Autism Spectrum Disorder/ or Autistic Disorder/	43,697
6	Down Syndrome/	26,774
7	Smith-Magenis Syndrome/	245
8	Rett Syndrome/	3,005
9	Lesch-Nyhan Syndrome/	1,244
10	Prader-Willi Syndrome/	3,329
11	Angelman Syndrome/	1,407
12	Fragile X Syndrome/	5,748
13	Cri-du-Chat Syndrome/	702
14	De Lange Syndrome/	916
15	Rubinstein-Taybi Syndrome/	578
16	1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15	176,151
17	(learning disab* or learning difficult* or learning disorder or learning impair* or intellectual* disab* or intellectual* impair* or intellectual dysfunction or development* disab* or development* disorder* or development* impair* or intellectual developmental disorder or mental* deficien* or mental* retard* or mental* handicap* or mental* disab* or mental insufficiency or mental* impair* or mental* challenged or IQ or subaverage intelligence or cognitive impair*).mp. [mp=title, book title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms, population supplementary concept word, anatomy supplementary concept word]	279,048

18	(autis* or Asperg* or Down Syndrome or trisomy 21 or Smith-Magenis or Rett* or Lesch-Nyhan or Prader-Willi or Angelman or fragile X or Cri-du-chat or Cornelia de Lange or de Lange or Rubinstein-Taybi).mp. [mp=title, book title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms, population supplementary concept word, anatomy supplementary concept word]	203,371
19	(special education* or special need* or additional support* or additional need*).mp. [mp=title, book title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms, population supplementary concept word, anatomy supplementary concept word]	18,343
20	17 or 18 or 19	461,480
21	16 or 20	466,035
22	Sex/	7,755
23	Sexuality/	7,880
24	Sexual Health/	2,675
25	Psychosexual Development/	3,568
26	Sexual Development/	1,168
27	Sexual Behavior/	68,649
28	22 or 23 or 24 or 25 or 26 or 27	86,762

29	(sex or sexuality or psychosexual behavior or sexual development or sexual health or psychosexual development or sexual behavior or psychosexual health).mp. [mp=title, book title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms, population supplementary concept word, anatomy supplementary concept word]	1,047,075
30	28 or 29	1,076,566
31	Education/	21,535
32	Curriculum/	89,102
33	(education or training or curriculum or program*).mp. [mp=title, book title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms, population supplementary concept word, anatomy supplementary concept word]	2,461,832
34	31 or 32 or 33	2,461,832
35	30 and 34	147,221
36	Sex Education/	9,395
37	(sex education or relationship* education).mp. [mp=title, book title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms, population supplementary concept word, anatomy supplementary concept word]	15,668
38	35 or 36 or 37	147,472



39	21 and 38	5,885
40	limit 39 to (English and journal article)	5,613

### **CINAHL Search Terms 23.03.24**

	<b>Query</b>	<b>Results from 23 Mar 2024</b>
S1	(MH "Intellectual Disability+")	36,986
S2	(MH "Persons with Intellectual Disabilities")	5,308
S3	(MH "Developmental Disabilities")	11,723
S4	(MH "Learning Disorders+")	10,968
S5	(MH "Autistic Disorder")	30,218
S6	(MH "Down Syndrome")	8,219
S7	(MH "Smith-Magenis Syndrome")	78
S8	(MH "Rett Syndrome")	670
S9	(MH "Prader-Willi Syndrome")	824
S10	(MH "Angelman Syndrome")	254
S11	(MH "Fragile X Syndrome")	1,118
S12	(MH "Cri-Du-Chat Syndrome")	105
S13	(MH "De Lange Syndrome")	111
S14	(MH "Rubinstein-Taybi Syndrome")	60
S15	S1 OR S2 OR S3 OR S4 OR S5 OR S6 OR S7 OR S8 OR S9 OR S10 OR S11 OR S12 OR S13 OR S14	86,633
S16	TI ( ("learning disab*" or "learning difficult*" or "learning disorder" or "learning impair*" or "intellectual* disab*" or "intellectual* impair*" or "intellectual dysfunction or development* disab*" or "development* disorder*" or "development* impair*" or "intellectual developmental disorder" or "mental* deficien*" or "mental* retard*" or "mental* handicap*" or "mental* disab*" or "mental insufficiency" or "mental* impair*" or "mental* challenged" or "IQ" or "subaverage intelligence" or "cognitive impair*" or "persons with intellectual disab*")) ) OR AB ( ("learning disab*" or "learning difficult*" or "learning disorder" or "learning impair*" or "intellectual* disab*" or "intellectual*	69,785

	impair*" or "intellectual dysfunction or development* disab*" or "development* disorder*" or "development* impair*" or "intellectual developmental disorder" or "mental* deficien*" or "mental* retard*" or "mental* handicap*" or "mental* disab*" or "mental insufficiency" or "mental* impair*" or "mental* challenged" or "IQ" or "subaverage intelligence" or "cognitive impair*" or "persons with intellectual disab*")) )	
S17	TI ( ( ("autis*" OR "Asperg*" OR "Down Syndrome" OR "trisomy 21" OR "Smith-Magenis" OR "Rett*" OR "Lesch-Nyhan" OR "Prader-Willi" OR "Angelman" OR "fragile X" OR "Cri-du-chat" OR "Cornelia de Lange" OR "de Lange" OR "Rubinstein-Taybi") ) ) OR AB ( ( ("autis*" OR "Asperg*" OR "Down Syndrome" OR "trisomy 21" OR "Smith-Magenis" OR "Rett*" OR "Lesch-Nyhan" OR "Prader-Willi" OR "Angelman" OR "fragile X" OR "Cri-du-chat" OR "Cornelia de Lange" OR "de Lange" OR "Rubinstein-Taybi") ) ) )	46,955
S18	TI ("special education*" or "special need*" or "additional support*" or "additional need*") OR AB ("special education*" or "special need*" or "additional support*" or "additional need*")	10,592
S19	S16 OR S17 OR S18	119,737
S20	S15 OR S19	153,700
S21	(MH "Sexuality+")	42,141
S22	(MH "Sexual Health")	9,086
S23	(MH "Sexual Behavior+")	54,008
S24	(MH "Psychosexual Development+")	10,239
S25	TI ("sex" or "sexuality" or "psychosexual behavio#r" or "sexual development" or "sexual health" or "psychosexual development" or "sexual behavio#r" or "psychosexual health") OR AB ("sex" or "sexuality" or "psychosexual behavio#r" or "sexual development" or "sexual health" or "psychosexual development" or "sexual behavio#r" or "psychosexual health")	191,024
S26	S21 OR S22 OR S23 OR S24 OR S25	228,687
S27	(MH "Education+")	1,037,040
S28	(MH "Curriculum+")	47,327

S29	TI ( training OR education OR curricul* OR program* ) OR AB ( training OR education OR curricul* OR program* )	821,219
S30	S27 OR S28 OR S29	1,517,661
S31	S26 AND S30	60,057
S32	(MH "Sex Education")	5,921
S33	TI ( "sex education" OR "relationship* education" ) OR AB ( "sex education" OR "relationship* education" )	4,007
S34	S31 OR S32 OR S33	61,526
S35	S20 AND S34	2,377
S36	S20 AND S34 (narrow by English and journal article)	2,247

### **ERIC Search Terms 22.03.24**

	<b>Query</b>	<b>Results from 22 Mar 2024</b>
S1	DE "Intellectual Disability"	3,669
S2	DE "Developmental Disabilities"	6,049
S3	DE "Autism Spectrum Disorders"	1,970
S4	DE "Down Syndrome"	1,552
S5	DE "Learning Disabilities"	19,661
S6	DE "Special Needs Students"	10,137
S7	S1 OR S2 OR S3 OR S4 OR S5 OR S6	40,785
S8	TI ("learning disab*" or "learning difficult*" or "learning disorder" or "learning impair*" or "intellectual* disab*" or "intellectual* impair*" or "intellectual dysfunction or development* disab*" or "development* disorder*" or "development* impair*" or "intellectual developmental disorder" or "mental* deficien*" or "mental* retard*" or "mental* handicap*" or "mental* disab*" or "mental insufficiency" or "mental* impair*" or "mental* challenged" or "IQ" or "subaverage intelligence" or "cognitive impair*") OR AB ("learning disab*" or "learning difficult*" or "learning disorder" or "learning impair*" or "intellectual* disab*" or "intellectual* impair*" or "intellectual dysfunction or development* disab*" or "development* disorder*" or "development* impair*" or "intellectual developmental	44,066

	disorder" or "mental* deficien*" or "mental* retard*" or "mental* handicap*" or "mental* disab*" or "mental insufficiency" or "mental* impair*" or "mental* challenged" or "IQ" or "subaverage intelligence" or "cognitive impair*")	
S9	TI (special education* or special need* or additional support* or additional need*) OR AB (special education* or special need* or additional support* or additional need*)	56,563
S10	TI ("autis*" OR "Asperg*" OR "Down Syndrome" OR "trisomy 21" OR "Smith-Magenis" OR "Rett*" OR "Lesch-Nyhan" OR "Prader-Willi" OR "Angelman" OR "fragile X" OR "Cri-du-chat" OR "Cornelia de Lange" OR "de Lange" OR "Rubinstein-Taybi" ) ) OR AB ("autis*" OR "Asperg*" OR "Down Syndrome" OR "trisomy 21" OR "Smith-Magenis" OR "Rett*" OR "Lesch-Nyhan" OR "Prader-Willi" OR "Angelman" OR "fragile X" OR "Cri-du-chat" OR "Cornelia de Lange" OR "de Lange" OR "Rubinstein-Taybi")	21,848
S11	S8 OR S9 OR S10	111,511
S12	S7 OR S11	123,138
S13	DE "Sex"	2,475
S14	DE "Sexuality"	9,522
S15	S13 OR S14	11,900
S16	TI ("sex" or "sexuality" or "psychosexual behavio#r" or "sexual development" or "sexual health" or "psychosexual development" or "sexual behavio#r" or "psychosexual health") OR AB ("sex" or "sexuality" or "psychosexual behavio#r" or "sexual development" or "sexual health" or "psychosexual development" or "sexual behavio#r" or "psychosexual health")	39,297
S17	S15 OR S16	44,556
S18	DE "Education"	4,597
S19	DE "Curriculum"	18,966
S20	DE "Training"	13,818
S21	TI ( training OR education OR curricul* OR program* ) OR AB ( training OR education OR curricul* OR program* )	998,148
S22	S18 OR S19 OR S20 OR S21	1,002,841
S23	S17 AND S22	19,323
S24	DE "Sex Education"	4,365

S25	TI ( "sex education" OR "relationship* education" ) OR AB ( "sex education" OR "relationship* education" )	2,331
S26	S23 OR S24 OR S25	20,536
S27	S12 AND S26	1,648
S28	S12 AND S26	552
S29	S12 AND S26	526

## **Appendix 2: Major Research Project**

### **Appendix 2.1: CORE-Q Checklist**

<b>No.Item</b>	<b>Guide questions/description</b>	<b>Reported on page #</b>
<b>Domain 1: Research Team and reflexivity</b>		
<i>Personal Characteristics</i>		
1. Interviewer facilitator	Which author/s conducted the interview of focus group?	Method Page. 69
2. Credentials	What were the researcher's credentials? E.g. PhD, MD	Title Page
3. Occupation	What was their occupation at the time of the study	Method Page. 70-71
4. Gender	Was the researcher male or female?	Method Page. 70-71
5. Experience and training	What experience or training did the researcher have?	Method Page. 70-71
<i>Relationship with participants</i>		
6. Relationship established	Was a relationship established prior to the study commencement?	Method Page. 66
7. Participant knowledge of the interviewer	What do the participants know about the researcher? e.g. personal goals reasons for doing the research.	Method Page. 66
8. Interviewer characteristics	What characteristics were reported about the interviewer/ facilitator? e.g. bias assumptions reasons an interest in the research topic.	Method Page. 70-71
<b>Domain 2: Study design</b>		
<i>Theoretical framework</i>		
9. Methodological orientation and theory	What methodological orientation? was stated to underpin the study e.g. grounded theory discourse analysis, ethnography, phenomenology content analysis.	Method Page. 65
<i>Participant selection</i>		
10. Sampling	How well participants selected? e.g. purposive, convenience, consecutive, snowball.	Method Page. 66
11. Method of approach	How were participants approached? E.g. face to face, telephone, e-mail.	Method Page. 66
12. Sample size	How many participants were in the study?	Method Page. 66
13. Non-participation	How many people refused to participate or dropped out? Reasons?	N/A
<i>Setting</i>		
14. Setting of data collection	Where was the data collected? E.g. home, clinic, workplace?	Method Page. 69
15. Presence of non-participants	Was anyone else present besides the participants in the researchers?	Method Page. 69

16. Description of sample	What are the important characteristics of the sample? E.g. demographic data	Method Page. 76
<i>Data collection</i>		
17. Interview guides	Were questions, prompts, guides provided by the authors? Was it piloted test?	Method Page. 67-69
18. Repeat interviews	Were repeat interviews carried out? If yes how many?	N/A
19. Audio/visual recording	Did the researcher use audio or visual recording to collect the data?	Method Page. 69
20. Field notes	What field notes made during or after the interview or focus group?	Method Page. 70-71
21. Duration	What was the duration of the interviews or focus group?	Method Page. 69
22. Data saturation	Was data saturation discussed?	Method Page. 66
23. Transcript returned	What transcripts returned to participants for comment and or correction?	N/A
<b>Domain 3: Analysis and findings</b>		
<i>Data analysis</i>		
24. Number of data coders	How many data coders coded the data?	Method Page. 70
25. Description of the coding tree	Did authors provide a description of the coding tree?	Results Page. 73
26. Derivation of themes	Were themes identified in advance or derived from the data?	Method Page. 70
27. Software	What software if applicable was used to manage the data?	Method Page. 70
28. Participant checking	Did participants provide feedback on the findings?	NA
<i>Reporting</i>		
29. Quotations presented	Where participant quotations presented to illustrate the themes/findings was each quotation identified? E.g. participant number	Results Page. 74-81
30. Data and findings consistent	Was there consistency between the data presented and the findings?	Discussion Page. 81-88
31. Clarity of major themes	Were major themes presented in the findings?	Results Page. 74-81
32. Clarity of minor themes	Is there a description of diverse cases or discussion of minor themes?	Discussion Page. 81-88

From: Booth, A., Hannes, K., Harden, A., Noyes, J., Harris, J., & Tong, A. (2014). COREQ (Consolidated Criteria for Reporting Qualitative Studies). In *Guidelines for Reporting Health Research: A User's Manual* (pp. 214-226).

<https://doi.org/https://doi.org/10.1002/9781118715598.ch21>

Appendix 2.2: Major Research Project Proposal

[OSF | Major Research Project Proposal April 2023.pdf](#)



Appendix 2.3: Ethics Approval Letter

Ethics Approval Letter removed due to confidentiality issues.

Appendix 2.4 Participant Poster

[OSF | Participant Poster.pdf](#)

Appendix 2.5: Demographic Recording Sheet

[OSF | Demographic Recording Form V1.pdf](#)

Appendix 2.6: Social Media App Logo Quiz

[OSF | Social Media App Logo Quiz.pdf](#)

Appendix 2.7: Interview Topic Guide

[OSF | Topic Guide V2.pdf](#)

Appendix 2.8: Participant Information Sheet

[OSF | Participant Information Sheet.pdf](#)

Appendix 2.9: Participant Privacy Notice

[OSF | Privacy Notice .pdf](#)

Appendix 2.10: Participant Consent Form

[OSF | Consent Form.pdf](#)



Appendix 2.11: Participant Debrief Form

[OSF | Debrief Form .pdf](#)