Dear Aoibhinn

With reference to your request for evidence for the Education Committee regarding relationships and sexuality education. Please find attached some of the research papers our team have published in the area of the needs of people with intellectual disabilities.

Regarding attending the committee, my colleague Professor Mark Linden and I are both available on either 20th November or 11th December, between 2-5pm.

We look forward to hearing from you.

Regards, Michael

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Note: I may send emails out of usual working hours. Please be assured that I do not expect a response outside of your working hours.

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The Experiences of Young People with Intellectual Disability, Parents and Professionals in Relationships and Sexuality Education Programmes: Findings from a Qualitative Study

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Abstract: People with intellectual disability want friendships and meaningful relationships, and some want intimacy. However, the expression of sexuality is an area where potential freedoms are often limited and restricted compared to their peers. While some relationships and sexuality education programmes do exist for this population, most focus on knowledge acquisition regarding sexuality and sex but lack in their focus on relationships, informed choices and decision-making. The aim of this study was to identify good practices and methods of delivery in relationships and sexuality education for children and young people with intellectual disability. A qualitative design was undertaken. Information about our study was distributed to eight special schools in the UK. Semi-structured interviews and focus groups were employed for data collection. Data from 37 pupils with intellectual disability, 11 parents and 16 healthcare and other professionals were thematically analysed. Following data analysis, three themes emerged: (i) seeking and sharing information; (ii) protecting and keeping safe; and (iii) learning for the future. The findings highlight that pupils are keen to learn about life changes and societal influences and want reliable information. Parents and professionals recognise that children and young people with intellectual disability will develop into adults and may be vulnerable when they leave the security of the school setting. They recognise that children and young people need to know about socialising, puberty, consent and contraception. Evidence-based programmes should be designed with these stakeholders to ensure children and young people with intellectual disability receive developmentally appropriate information to make happy and safe decisions about their relationships.

Keywords: relationships; sexuality; education; intellectual disability; health; qualitative

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1. Introduction

The population of children and young people with intellectual disability is increasing and ageing, with more living into adulthood with a range of neurodevelopmental, physical, behavioural and mental health needs [1]. The changes are due to improvements in neonatal intensive care, wider health and social care services and access to care and support [2]. Children and young people with intellectual disability often have more complex support needs compared to typically developing children, particularly in understanding, learning and remembering new information and skills [3]. Some may require additional support with everyday activities such as communication, keeping safe and undertaking everyday tasks [4]. Consequently, many will require specialist services at some point in their lives [5].

There have been significant policy changes and developments over recent decades regarding the education of children and young people with intellectual disability, with moves

towards inclusive education [6]. One recent educational development has focused on the right of children and young people with intellectual disability to experience relationships and express their sexuality [7]. While parents may be offered educational provision for their child to attend the same school as their typical peers [8], some children, due to their specific learning and support needs, may attend a blend of mainstream and special education provision [9]. For other children, notably those with the most complex educational and support needs, full-time attendance at a special education provision may be viewed as the most appropriate option [8]. A special school is a school that caters specifically to children and young people whose needs cannot be met with the provision and support provided by a mainstream school. This encompasses children and young people with many different types of educational needs [10].

The existing policy and research evidence recognises the rights of people with intellectual disability to lead fulfilling lives and make life choices [11–13]. People with intellectual disability want friendships and meaningful relationships, and some want intimacy [14]. However, the expression of sexuality is an area where potential freedoms are often limited and restricted compared to their typical peers [15]. People with intellectual disability are often misperceived as being either asexual, hypersexual or sexually immature [16]. Additionally, evidence highlights issues related to autonomy versus vulnerability, exploitation or risk of harm when supporting young people with intellectual disability to make decisions regarding their sexual activity [17]. There is a need to develop the understanding of families and professionals in education, social care and health services that many people with mild and moderate intellectual disability are interested in and actively engage in sexual relationships [14,18]. However, they possess less knowledge about relationships and sexuality, display more inappropriate sexual behaviours and often do not understand the consequences of engaging in unprotected sex [19]. Some practice unsafe sex, are less likely to use contraception, have an increased risk of having an unplanned pregnancy and have greater exposure to HIV and sexually transmitted infections (STIs) compared to typically developing young people [14,20]. Young people with intellectual disability may be at greater risk of sexual abuse and exploitation [21]. Some also experience difficulties in forming and maintaining relationships, resulting in loneliness and social isolation [20,22]. Current research evidence indicates that young people with intellectual disability may not have proper access to suitable relationships and sexuality education programmes [16]. While some relationships and sexuality education (RSE) programmes do exist for this population, most focus on knowledge acquisition regarding sexuality and sex, lacking in their focus on relationships, informed choices and decision-making [23]. Furthermore, existing programmes have not typically included the voices of children and young people with intellectual disability, parents and professionals involved in their education, care and support; therefore, potential RSE programmes should involve them. However, despite these issues, there remains a definitive gap in the delivery of RSE programmes that specifically address relationships and sexual needs and concerns for this population [14].

It is unclear what is currently being delivered in special schools and the process of evaluating and identifying outcomes in ways that meet the needs of children and young people with intellectual disability whilst also addressing parental concerns. Therefore, limits in consistency in provision and delivery may ultimately impact life choices and place the health and well-being of children and young people with intellectual disability at risk. Therefore, healthcare and other professionals have important health education roles in meeting the needs of children and young people with intellectual disability, including those related to relationships and sexuality [24]. They are well placed to work with children and young people with intellectual disability and their parents to ensure that RSE needs are identified and effectively addressed.

The aim of this study was to explore the views and experiences of children and young people with intellectual disability, parents and professionals in the provision of RSE programmes in special schools across the UK. This paper presents a more detailed and

comprehensive analysis of the study findings that were reported in part in the final report commissioned by the funder [25].

2. Materials and Methods

2.1. Design

A qualitative design involving semi-structured individual interviews and focus groups was adopted. All participants were provided with information about our study and a consent form that was completed prior to the interview or focus group. Accessible information and consent forms were provided to the pupils. The interviews and focus groups collected data on the views and experiences of participants in the delivery approaches regarding RSE for children and young people with intellectual disability in special school settings.

2.2. Participants

Eight special schools across England, Northern Ireland (NI), Scotland and Wales were identified by the research team and, following an invitation, took part in this study. In each participating school, the principal, or a designated teacher, acted as a gatekeeper to identify pupils, parents and professionals who met the inclusion criteria and were willing to participate. The potential participants were then issued letters of invitation and information about our study. All participants were required to speak and understand English. Children and young people with profound and multiple intellectual disability were not included due to their communication abilities. The gatekeeper in each school made this determination based on their detailed knowledge of the pupils' individual capabilities to participate in this study. Health professionals were approached through the existing contacts of the research team.

Although not a requirement, all pupils and professionals had experience participating in relationships and sexuality education.

Over a period of 13 months from February 2022 to February 2023, a total of 64 participants, comprising 37 pupils with intellectual disability aged between 12 and 19 years, 11 parents and 16 health, social care and education practitioners, provided informed consent and subsequently took part in an interview or focus group. A further 26 who did not participate included 10 pupils who became ill or whose parents did not provide consent and 5 parents and 11 professionals who were contacted on a number of occasions and did not respond. Table 1 shows the demographics and groups of those who participated across the United Kingdom.

Table 1. Demographics and groups of participants across the United Kingdom.

Region	Pupils	Parents	Professionals	Total
England	5	3	5	13
Northern Ireland	24	6	8	38
Scotland	5	0	1	6
Wales	3	2	2	7
Total	37	11	16	64

2.3. Data Collection

A Microsoft Teams online interview took place with 13 pupils and a face-to-face interview with 4; most were supported by a member of education staff. Pupil interviews lasted between 10 and 22 min. The remaining 20 pupils took part in two focus groups for boys or girls, with each group having education staff present for additional support. The boys' group had a total of 12 participants, lasting 34 min. The girls' group comprised eight participants and lasted 39 min.

Semi-structured individual interviews took place with 11 parents of children and young people with intellectual disability and 16 health, social care and education practitioners. Each interview lasted between 14 and 51 min for parents and between 26 and 66 min

for professionals. Interviews took place via Microsoft Teams, telephone or in person at the school or parents' home.

Two focus groups comprising five and four professionals took place via Microsoft Teams and lasted 53 and 33 min, respectively.

The interview and focus group questions centred on the participants' views on and experiences of RSE programmes, for example, "What is your experience of RSE programmes for your child?"; the identification of topics for inclusion in an RSE programme, for example, "What would you like your parents and teachers to tell you about relationships and sexuality?"; and the identification of examples of good practice and preferred methods of delivery, for example, "What do you think are the best methods to teach young people with intellectual disability about RSE?".

The study research fellow (FM), who had no prior interaction with the participants, conducted all interviews and focus groups. Participants did not receive any gratification for taking part in this study.

All interviews were recorded and transcribed verbatim and then anonymised by removing all identifiable information and assigning a numerical identifier.

2.4. Data Analysis

The research team read each transcript separately to gain an understanding of the participants' views and experiences. The coding of data into categories was performed by the research fellow and checked for consensus by the first author. The analysis of the data was facilitated by the data management programme NVivo 12 [26]. As part of the analysis process, themes and subthemes were systematically identified. Consequently, the proposed themes and subthemes were then discussed by the research team, with disagreements resolved and consensus reached. The approaches used in the qualitative data analysis and synthesis were rigorously followed to ensure trustworthiness, dependability and credibility throughout the process [27].

3. Results

Three broad themes emerged following data analysis that were associated with the development, delivery and evaluation of RSE programmes. These comprised the following: (i) seeking and sharing information; (ii) protecting and keeping safe; and (iii) learning for the future.

3.1. Seeking and Sharing Information

The demand for information on RSE amongst the pupils was evident from the data. All pupils had participated in RSE programmes of various durations. In the absence of a defined curriculum, the topics addressed had extended from 'how to be a good friend' to more in-depth information about consent, sex and contraception. In addition to classroom teaching, some pupils had also received information from friends and family, either through informal conversations or proactive approaches. Others had searched the internet and watched YouTube videos for information they were curious about.

There was an eclectic mix of professionals delivering RSE programmes to young people. Primarily, this involved teachers and teaching assistants from within their special school who had varying levels of knowledge, expertise and confidence in the subject. To assist with the delivery in special schools, external educators with expertise in RSE programme delivery were occasionally engaged. These ranged from school nurses and social workers from local health and social services to trainers from independent agencies specialising in RSE.

Parent participants were supportive of special schools in the delivery of RSE programmes. All participants considered it important, though, to be kept informed of RSE programme content, what was being taught and when. In contrast, others had attended workshops within the special school to gain a detailed insight into the programme content and delivery. Some parents expressed a need to be prepared to support their children and

young people at home in case they asked questions and sought more information, thereby highlighting their development needs.

> *"I get my information from online, [teacher], or anyone else willing to teach me. . . I learn from other people."* (Pupil 2, age 15)

> *"I learned about like proper consent from You Tube videos. And the school actually did, like, do like a presentation thing about it, which is nice."* (Pupil 13, age 17)

> *"It's important to learn because if you don't know then you don't know what's happening to your body."* (Pupil 23)

> *"This stuff's so important. My kids think, mum, you are out of your mind, but like, why do you have to be so open. I am like, because no one was ever open with me and I want you guys to feel that it is not taboo. I want them to be able to, you know, they can giggle, but they need to know what's appropriate to say and do."* (Parent 9)

> *"It's still almost seen as a taboo thing. I don't know, maybe, yeah, certainly from the people I've worked with that have come out of schools, nobody has come forward talking about that subject, and I think just making it a little bit more relaxed would be helpful."* (Professional 16)

3.2. Protecting and Keeping Safe

Parents were aware that their children and young people were potentially vulnerable to predators online and in the community, recognising the need to protect them and keep them safe. Some parents reported having involved the police and school after their child had experienced unpleasant interactions online. All parents and professionals agreed that online safety and awareness and safety in relationships should be included in RSE programmes. One parent expressed concerns about their child's safety and what would happen to them when they could no longer provide care.

The need to maintain a healthy and safe lifestyle was also recognised as important. Professionals and some parents were open to including information on consent, contraception and sexually transmitted infections (STIs) for young people. Some schools included information on health checks and the importance of breast and testicular screening, with one arranging 'bra fitting' trips to a local shop to emphasise the importance of looking after yourself.

The children and young people engaged in RSE learning and most understood their responsibilities regarding the content delivered within the programmes as well as the possible implications and consequences on their lives in the future, such as unintended pregnancy. This was evident across all ages, particularly in respect of online safety, and, for some young people, the prospect of cyber bullying, ending up in a coercive and abusive relationship or having an unintended pregnancy were to be avoided.

> *"It's about keeping you safe. It's about being aware of the world out there because my mum said there's some bad people that might make you feel uncomfortable."* (Pupil 25)

> *"I reckon it's so important because like, it can be too late and then a baby comes. Then practically your childhood's ruined because you have a baby and all your friends are going out to clubs or whatever, and you're sitting in the house minding a baby."* (Pupil 33, age 15)

> *"If he [son] can't interact safely with people once I'm gone, then, you know, what happens."* (Parent 1)

> *"Relationships, sexual education is important in one sense to help provide an understanding of one's body, but also probably to provide a level of protection as well. Because if they don't understand what's appropriate or inappropriate, they don't understand where the boundaries are, then ultimately, they can become left in very vulnerable positions and people don't understand."* (Parent 5)

> *"Our children should be allowed to access the community and have a full life and they need to be given the tools to protect themselves and know about what is right and wrong and what's acceptable to them."* (Professional 8)

3.3. Learning for the Future

Both parents and professionals were aware that, as children and young people with intellectual disability matured and aged, the need for RSE took on greater importance. Discussions regarding puberty and the ageing process were openly conducted with pupils by all the professionals and some parents who were involved in the delivery of all the RSE programmes in school and at home. Some parents were proactive in educating their children, notably when a school had not focused on a specific issue and where they considered the information was important and required. This was particularly relevant for parents who had daughters with intellectual disability, where they had been proactive and creative in sharing information about the menstrual cycle and pregnancy prior to menstruation commencing. Awareness of different sexualities was discussed in most of the RSE programmes, with some pupils sharing their own experiences and sexuality.

There was consensus that learning should continue into adulthood and throughout life. This was viewed as necessary to reinforce and build upon the education provided and develop more relevant knowledge as young people aged, formed new relationships and experienced different situations. The apparent absence of age-appropriate and evidence-informed RSE programmes for adults and older adults with intellectual disability was viewed as a gap that needed to be addressed.

> *"I think sometimes there is that preconceived idea that people who have got learning disabilities are not going to have their own relationships. And we know that just isn't true, but their relationships may be very different. And I think again, it's looking at those wider parameters of what a relationship looks like. So, it's not necessarily about sex, but it's about all of the other components and that they're all as equally important."* (Parent 11)

> *"These children are going to turn into adults and you want them to be able to go out into the community and understand, you know, the socially appropriate behaviours and the way we live and understand their own feelings and their own sexualities. You know, if it wasn't talked about, what if you had a child with learning disabilities who themselves was say transgender."* (Parent 2)

> *"When my daughter leaves school, she will be going on to different day care facilities, or whatever, day programmes, that is the word I am looking, and she will be meeting new people. She will have new facilitators, new carers, so she has to learn. And she is out in the big bad world as well, so that learning has to continue."* (Parent 4)

> *"I'm bi so I like girls and boys. Yeah, so, it like helps me know what I like and what I am attracted to."* (Pupil 28)

> *"It's not a school that makes a child, it's not an individual that makes a child, it's community that makes a child. And I think as well as getting great resources for school, we need to be doing better support for our parents in that as well and making it a fully holistic approach to it, because they need to be seeing it not just in schools but in their homes. In the next part of their life they go to, they need to see all those aspects and be able to explore it safely in those as well."* (Professional 4)

4. Discussion

There have been significant policy changes and developments over the past fifty years regarding the rights of children with disabilities, including the right to inclusive education and additional support [11,28]. These developments have focused on both inclusion in mainstream schooling and special school options [6,9]. For some parents, special schooling may be the preferred option for their child, particularly for those with more complex learning and support needs [8]. Whatever the model provided, the primary focus is on

meeting the learning needs of the individual child. With the move towards inclusive, needs-led education for children and young people with intellectual disability, the role of RSE has been identified as an area requiring attention and development [7]. Curriculum developments are necessary to ensure the distinct needs and learning styles of children and young people with intellectual disability are recognised and addressed [23].

The findings from this study highlight the need for and importance of children and young people with intellectual disability participating in RSE programmes that are both accessible and specific to their needs and concerns. The study findings have sought to bring together and report on the perspectives of children and young people with intellectual disability, their parents and the professionals involved in their education, care and support. All have unique and important perspectives relevant to the development and content of RSE programmes and their planned delivery. From the study findings, it is evident that all participants were of the view that RSE programmes play an important role in the development of knowledge and understanding regarding relationships and the expression of sexuality. Many children and young people with intellectual disability have developed information technology (IT) skills, seek information and already engage in the use of social media. Providing support and access to RSE that enables informed decision-making and choices is a fundamental right of children and young people that needs to continue across their lifespan. Parents recognise the need for RSE programmes and the important role they play in educating children and young people with intellectual disability and in keeping them safe. Professionals appreciate the value and benefits gained by children and young people with intellectual disability from RSE programmes, recognising the requirement to both standardise and tailor content based on their needs and level of intellectual impairment. Collectively, the findings from the current study and wider research evidence have implications for future policy, practice, education and research.

4.1. Implications for Policy

In the past few years, with the strategic policy focus on RSE programmes being integrated within the school curriculum, there has been an opportunity to ensure that all developments and initiatives are fully inclusive of and reflect the needs and concerns of children and young people with intellectual disability, their parents and the professionals involved in the design, delivery and evaluation [29]. To reflect local policy, government and education providers should ensure there is specific reference to the distinct education and support needs of children and young people with intellectual disability and how they will be addressed and integrated within the curriculum. To effectively support RSE programme development and implementation in special school settings, agreement regarding core content that proactively includes the voices of children and young people with intellectual disability and their parents is necessary to ensure that all issues and concerns are recognised and responded to [30]. This is important from the outset, as particular aspects of RSE programme content may be viewed as contentious by some, such as capacity and consent, same-sex relationships and social media concerns such as pornography, sexting and cyber bullying [31,32]. Two specific policy areas require further attention and development. The first is the evaluation of the impact and outcomes achieved over time by participating in an RSE programme [33,34]. While children and young people with intellectual disability report enjoyment and enthusiasm from participating in RSE programmes, it remains to be established the extent to which learning can be generalised to real-life situations [34]. Identifying the impact of participation on concerns such as STIs, unintended pregnancy and child protection issues is essential. These are areas to focus on in future research to identify the impact on forming and sustaining relationships, health and well-being and longer-term outcomes [35]. The second relates to the importance of recognising and responding to the needs of adults and older adults with intellectual disability. To date, there has been limited attention given to RSE programmes that are reflective of the needs and aspirations of this cohort, and this is an area requiring policy attention and development [36].

4.2. Implications for Practice

From a practice perspective, there are implications arising from the study findings. Practitioners need to be prepared with the necessary knowledge and skills to effectively identify content relevant and appropriate to children and young people with intellectual disability in the development and delivery of RSE programmes [9,37]. To enable effective delivery, practitioners need time to engage with and involve children and young people with intellectual disability and their parents in the design and delivery of the programme [24]. With the diversity of populations and communities, practitioners involved in delivery need to identify and address cultural and religious beliefs in a way that is sensitive and acceptable [38]. Careful planning and involvement from the outset can help to answer questions, allay concerns and maximise benefits [35,38]. From a practice development perspective, access to networks of professionals engaged in RSE programmes can enable the sharing of best practices and help to build knowledge and confidence [33]. Current evidence highlights that the programmes are enjoyable for participants, yet it is less clear how learning is applied and generalised to the realities of life [37]. An important finding from this and other studies is the need to build in an evaluation of the learning gained by children and young people with intellectual disability from participating in RSE programmes from the outset. Therefore, practitioners need to consider and identify, as an integral part of planning, how the learning from participation will be evaluated [29]. Consideration also needs to be given to obtaining the views and experiences of parents regarding the benefits derived from participation and areas where further learning may be required [37].

4.3. Implications for Education

With the focus on integrating RSE programmes within the school curriculum as a core subject, there is a need to identify and meet the education and development needs of children and young people with intellectual disability, their parents and practitioners. Children and young people with intellectual disability require access to RSE programmes that are responsive and reflective of their needs, hopes and aspirations [39]. The education needs and concerns of parents and families also need to be identified and included [14,18]. RSE programme development, delivery and evaluation should be central to the education of practitioners. This is necessary and important as the findings from this study and the wider research literature highlight that practitioners often lack knowledge, skills and confidence around RSE [36,39]. Therefore, it is important to provide training at an undergraduate preparation level for teachers, social workers, nurses and others, integrating core content across the curriculum. This can start with the concepts of friendships and relationships, moving on to consider sexuality as young people with intellectual disability grow, mature and move into adulthood. At a postgraduate level, there is the opportunity to further develop this education [36].

4.4. Implications for Future Research

Conventions and statements regarding the rights of all people with disabilities have begun to positively impact the lives of some people with disabilities, including children, adults and older people with intellectual disability [11,28]. Inclusive to them are their relationship and sexuality needs and their right to have them identified and effectively addressed. The evidence base of what works to produce positive individualised outcomes must expand as a result of this research [40]. The research evidence, theories and behaviour change models used in the development of RSE programmes are an under-researched area and one that requires considerable attention. Undertaking research studies involving statistically appropriate samples to evidence significant effects is challenging [14,41]. To address these challenges, future RSE studies should, for example, adopt cluster randomised designs involving groups of special schools for children and young people with intellectual disability. Using this approach would allow for the effect of an RSE programme intervention on an entire school and a larger cluster to be identified. Children and young people and their

parents want to be involved in and at the heart of RSE programme development, another area ripe for research focus. An important gap in the existing research evidence relates to the wider long-term benefits and outcomes derived from participating in an RSE programme. Future studies could identify, for example, reductions in unintended pregnancies, decreases in sexually transmitted infections and safeguarding concerns. Undertaking research in these areas will increase the evidence of outcomes achieved, the impact that RSE has on the lives of children and young people with intellectual disability in supporting informed decisions and how this can improve their quality of life.

4.5. Strengths and Limitations

The current study promotes the voice of children and young people with intellectual disability, parents and professionals regarding their experiences with RSE and its future requirements. The findings from this study add to our understanding of and provide further insights into the acceptance, content and delivery approaches of RSE for children and young people with intellectual disability, specifically in special school settings. A strength of this study is the participation of children and young people with intellectual disability. This is important as their views and experiences have been relatively silent in the research literature so far. The range of professionals who participated in this study reflects those with direct knowledge and experience of delivering RSE programmes to children and young people with intellectual disability. Some of the interviews with children and young people with intellectual disability were shorter than those with adults, which was primarily due to communication issues and their level of ability to engage in the interview more fully. However, including their views and experiences is vital in an area that has attracted limited attention thus far and is a particular strength of this study. Although the response rate from parents was good, it is recognised that there may be bias in the sample. Parents who participated in this study, for example, may not be fully reflective of the wider parent population and their views. While significant attempts were made to recruit all participants from across sites, it proved challenging, notably for some professionals and parents.

5. Conclusions

The evidence base regarding relationships and the expression of sexuality in children and young people with intellectual disability is growing and evolving. These developments are important and necessary by way of ensuring equality and protecting the rights of this, at times, vulnerable population. Failure to ensure that all children and young people with intellectual disability have access to RSE places them at potential risk of harm and avoidable sequelae that may have significant implications for their health and well-being, not just in childhood and adolescence but across their lifespan and into adulthood. What is apparent from the findings of the current study is that children and young people want and need access to education and support to enable the development of friendships and relationships and express their sexuality. Likewise, parents of children and young people want their children to participate in RSE programmes, recognising that RSE is an empowering process and experience that provides information to enable choice and informed decision-making. Professionals involved in the education, care and support of children and young people are key to the effective delivery and evaluation of RSE programmes specific to the needs of the population in special school settings. There is a need for further work to be undertaken to develop and empirically test RSE programmes that are sensitive and specific to the needs of these children and young people.

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Informed Consent Statement: Informed consent was obtained from all subjects involved in this study.

Data Availability Statement: Data are contained within the article.

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Learning for life, friendships and relationships from the perspective of children and young people with intellectual disabilities: findings from a UK wide qualitative study

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Abstract

Background Relationships and sexuality education (RSE) programmes are widely taught in schools, however for children and young people with intellectual disabilities, these programmes appear to be limited regarding information on relationships, informed choices and decision making. The purpose of this study was to seek the views and understanding of children and young people with intellectual disabilities, and those involved in their care and education, to identify best practice and approaches to the delivery on relationships and sexuality education.

Methods This study used a qualitative design with 37 pupils from five special schools from across the United Kingdom (UK) participating. In-depth semi-structured interviews were held online, or in person. All interviews were recorded and transcribed verbatim. Transcripts were anonymised, assigned a pseudonym and subjected to inductive thematic analysis.

Findings Four themes emerged from the data: (i) enthusiasm and inquisitiveness to acquire knowledge; (ii) dynamics of positive friendships; (iii) experiences and understanding of supportive relationships and sexuality; and (iv) valuing the exchange of knowledge and information. The findings highlight that children and young people with intellectual disabilities want education, support and information on matters relating to their relationships and sexuality.

Conclusions This is the largest study to date providing a voice to children and young people with intellectual disabilities regarding their relationships and sexuality. While special schools provide relationships and sexuality education, there is a requirement for a programme and resources specific to the needs of pupils with intellectual disabilities to be developed and evaluated. Such education should continue beyond school and be embedded in adult services.

Keywords Children, Health, Inclusive education, Intellectual disabilities, Pupils, Qualitative research, Relationships, Sexuality, Special schools, Young people

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Background

Relationships and Sexuality Education (RSE) programmes are widely taught in schools. All UK schools are required to offer accessible and inclusive RSE to all pupils, including those with special educational needs and disabilities (SEND) [1–5].

The aim of RSE is to provide children and young people the information they need to help develop healthy, nurturing relationships of all kinds, including intimate ones. According to Barbagallo and Boon [6], previous RSE programmes focused on human reproduction and sexual organs [7], and lacked the teaching of emotions, relationships, and sexual health and well-being. However, more recently RSE has been considered a lifelong process of acquiring information, building respect for self and for others, and forming attitudes and ideologies about topics such as identity, relationships, reproduction, sexual health, and intimacy [8].

The past several decades has seen increased attention on the sexual rights and needs of people with intellectual disabilities, and their importance has been highlighted in several international policy reports [9–11]. However, despite the rights to RSE for all children and young people with intellectual disabilities being enshrined in the United Nations Convention on the Rights of the Child, (Article 25a) [12], evidence-based and rigorously tested RSE programmes appear to be absent.

There are challenges faced by pupils with intellectual disabilities in accessing comprehensive RSE information. This is attributed to some teachers omitting sexuality related content in RSE programmes and teaching delivery and lack of accessible resources [13, 14]. Studies have identified that young people and adults with intellectual disabilities are not provided with adequate relationships and sexuality education to prepare them for future relationships, sex and parenthood [13, 15]. Furthermore, many do not receive sexuality education that is orientated to their needs and development, promotes a positive image of sexuality, or enables and supports informed decision making [16]. Evidence across a 20-year study showed that children and young people with intellectual disabilities continue to be less likely to receive sex education [17, 18], notably those with profound and multiple intellectual and multiple disabilities. Carter et al. [13] assert that exclusion from RSE can have consequences for the sexual and reproductive health and well-being of people with intellectual disabilities. While the reticence to provide appropriate RSE is often rationalised with the intention of protecting vulnerable children and young people with intellectual disabilities, this may leave them more vulnerable to the potential of sexual violence, harm and exploitation [19].

The needs of children and young people with intellectual disabilities concerning sexuality and privacy are like their typically developing peers without intellectual disabilities with research evidencing that they find RSE helpful in addressing their needs [16, 20, 21]. Moreover, children and young people with intellectual disabilities may not have had the experiences to develop social skills for long-term relationships, even though they place a high priority on having friends and a desire to be more knowledgeable about sexuality [22, 23]. Children and young people with intellectual disabilities have the same desires regarding sexuality and reproduction as those without intellectual disabilities yet some continue to face restrictions in making choices about their bodies and developing friendships and intimate relationships [24–27].

Parents and teachers however may withhold information from children and young people with intellectual disabilities, to shield them from knowledge of the potential harms and threats that may exist in society [28, 29]. In schools, there are few RSE curricula specifically adapted for pupils with intellectual disabilities, with little evidence regarding the effectiveness, with notable exceptions using peer education approaches [25, 30]. Education regarding sex, particularly in the context of intellectual disability, appears to depend on what teachers are knowledgeable and comfortable delivering [28, 29]. The format of current RSE programmes have not been uniformly developed or evaluated. Brown et al., [31] identified the need to include people with intellectual disabilities in the planning phase of an education programme to ensure their needs and concerns are included and addressed. While adapted RSE for children and young people with intellectual disabilities is relevant and necessary, the wider knowledge and understanding about their specific views and perceptions remains limited. This may be attributed to the challenges of conducting such studies, as the range and presentation of intellectual disabilities may potentially impact on the ability of some to consent and participate in research studies.

The aim of this study was to explore the views and experiences of children and young people with intellectual disabilities, parents and professionals in the provision of RSE programmes in special schools across the UK. Due to the scope and extent of the wider dataset this paper provides a more detailed analysis of findings from the main data [32]. Data specific to the voice of pupils with intellectual disabilities were extracted for furthermore detailed analysis and are presented in this paper.

Methods

Design

A qualitative design was utilised for this study involving in-depth semi-structured and focus group interviews. An easy read information sheet and consent form were prepared for pupils with intellectual disabilities. The

interviews and focus groups provided an in-depth understanding of pupils with intellectual disabilities' experiences of relationships and sexuality education. Ethical approval was gained from an institutional review board at the lead author's University (Ref: MHLS 19_19).

Participants

Five special schools across England ($n=1$), Northern Ireland ($n=2$), Scotland ($n=1$), and Wales ($n=1$) took part in the study. Special schools accommodate pupils whose educational needs cannot be met within mainstream schools. The focus is on the pupil's individual needs and learning styles with appropriate teaching support and additional therapies and supports provided. Class sizes are smaller comprising pupils with similar needs rather than age [33]. Potential pupil participation in the study within each school was determined by a gatekeeper, who was the principal or a designated teacher. The gatekeeper knew the pupils and was best placed to judge their capacity to consent and likely willingness to participate. A total of 37 pupils participated from England ($n=5$), Northern Ireland ($n=24$), Scotland ($n=5$) and Wales ($n=3$). The age of pupils ranged from 11 to 19 years, and all were able to understand and articulate responses to the research questions. The demographic details of the pupils are shown in Table 1.

Data collection

A gatekeeper in each school identified pupils willing to participate in an interview or focus group and issued letters of invitation and information about the study to the children and their parents. The researcher liaised with each gatekeeper to arrange interviews with their consent. Prior to participation all pupils were required to complete an accessible consent form, with a parent also providing written assent. They were informed of the right to withdraw from the study at any time, without giving any reason; limits of confidentiality and data protection; and an option to being contacted and invited to take part in future studies of a similar nature with no obligation.

The research team developed an interview guide that included probing questions and prompts for the study (see supplementary material 1). The researcher used this guide in all individual and focus group interviews to ensure consistency. Interview questions were open-ended to encourage participants to provide detailed responses regarding experiences of RSE programmes, and understanding of relationships, sexuality and consent. Examples of good practice, methods of delivery and topics for inclusion in an RSE programme were also explored.

Individual interviews took place with 13 pupils via Microsoft Teams, and 4 pupils face-to-face. Interviews lasted between 10 and 22 min. The remaining 20 pupils took part in two focus groups from one school consisting of an all-boys or all-girls group. The boys' focus group had a total of 12 participants and lasted 34 min; while the girls' focus group had a total of 8 participants and lasted 39 min. Each focus group, and some interviews, had a member of staff present for additional support.

All individual and focus group interviews were recorded and transcribed verbatim. Transcripts were anonymised by removing all identifiable information and assigning each participant a pseudonym.

Table 1 Demographic details of pupils

Characteristics	Category	Number	(%)
Gender	Male	23	(6)
	Female	14	(38)
Age	11	1	(3)
	12	1	(3)
	13	2	(5)
	14	3	(8)
	15	4	(11)
	16	2	(5)
	17	2	(5)
	18	1	(3)
	19	1	(3)
	Boys group 13–19	12	(32)
	Girls group 12–19	8	(22)
Country	England	5	(13)
	Northern Ireland	24	(65)
	Scotland	5	(14)
	Wales	3	(8)

Data analysis

The six phase approach by Braun and Clarke [34] was used to guide data analysis. First, the research team independently read the transcripts to gain an understanding of the participants' experiences. Next the transcripts were thematically analysed by each member of the research team to identify key themes. Following this, the transcripts were discussed as a team to identify and agree the final themes [34]. NVivo 12 [35], a data management programme, was used to facilitate analysis and management of the data. The approaches to data collection and analysis were rigorously followed by the research team to ensure the credibility, trustworthiness and dependability of the process which included investigator triangulation, audit trail of interviews, and thick, detailed description [36, 37].

Rigour

In addition to the application for ethics approval, a research protocol was prepared and peer [34] reviewed. To ensure consistency across interviews and focus groups the same researcher (FM) conducted all data collection using an interview guide and transcribed recordings. This ensured accurate transcripts guaranteeing

precise representation of participants' perspectives. The researcher had extensive experience of conducting interviews and focus groups involving people with intellectual disabilities. The data analysis attained credibility through meticulous validation by all members of the research team.

Findings

Four themes emerged following analysis of the data: (i) enthusiasm and inquisitiveness to acquire knowledge; (ii) dynamics of positive friendships; (iii) experiences and understanding of supportive relationships and sexuality; and (iv) valuing the exchange of knowledge and information.

Enthusiasm and inquisitiveness to acquire knowledge

There was enthusiasm amongst all the pupils with intellectual disabilities to learn about RSE, and they also wanted the opportunity to extend their learning beyond the school years. This yearning for knowledge ranged from understanding body parts, friendships, puberty, and how to form relationships, to how to have a baby and not just how to prevent such an occurrence. There were many different modes of delivering such information, both in the classroom setting and at home from family members such as parents and grandparents. However, irrespective of the educator, it was important to the pupils that the "truth" (Pupil 31, age 14) and clear information was given. Whilst some pupils were not allowed access to social media, or had removed themselves due to negative experiences, others were using social media and accessing the internet for information. RSE was considered as advantageous amongst the pupils, with one stating they had learned "to be safe and watch out, and take care of yourself" (Pupil 34, age 15). Nevertheless, one pupil came to the realisation that the internet "is a very dangerous place" (Pupil 25, age 12–19) with others being aware of the importance of following guidance from parents and other family members to keep them safe.

> *I think even after school as well. Like it's always expanding, like relationships and things and there's always like new things to learn about with it. (Pupil 12, age 18)*
>
> *I get my information from online, Mrs [teacher], or anyone else willing to teach me … Some of it I have self-teached myself and others it's from teachers. I sort of give it variety. Some of it I learn and self-learn and others I learn from other people. (Pupil 2, age 15)*
>
> *I have been learning it [RSE] with my parents. My parents have been privately talking about it as well … what I found is, my parents tell me the right way about relationships and the right way because some people might say it the other way and it can't be true. (Pupil 25, age 12–19)*
>
> *How they talk about consent, it's very good, yes or no. Not maybes, just yes and no. And they talked about the ages what was very good, I think. And how you can get in a lot of trouble. (Pupil 33, age 15)*
>
> *I feel safe because I have had plenty of guidance. So, my sister is connected to me. And my mum looks at my phone all the time. So, I feel safe. (Pupil 25, age 12–19)*

Dynamics of positive friendships

The dynamics of having or being a friend were well articulated by the pupils with descriptive words such as "nice", "helpful" and "polite". The importance of having a supportive friend in terms of listening and talking about problems was recognised by some as valuable and much needed. This was characterised with the need for the person to be honest and trustworthy. Friendships were predominately forged in school with few of the pupils having friends in other settings such as sports clubs and their local neighbourhood. The use of social media platforms was prevalent amongst the pupils with many feeling safe while using them. However, this was primarily for keeping in touch with both their school friends and family members. Irrespective of where they liaised with their friends, the pupils were mindful of the importance of treating each other well and having respect. Where these values were compromised, the pupils had no hesitation terminating friendships or blocking contact online.

> *Somebody you can trust. Somebody you can see every now and then. Being there for you. Sometimes I listen to their problems. I calm their nerves sometimes if they are really nervous. I tell them all it's going to be ok. (Pupil 31, age 14)*
>
> *I have only got friends what are in school what I play with on Xbox and games. That's where we chat. (Pupil 3, age 13)*
>
> *The only difference between a friendship online and offline is online you don't really see much of their face or where they are. Which is why I often tend to say if you want me to be your friend you need to meet me in person. We need to meet in person so I know you better … And if they keep trying it, I just block them and if they continue to try it, I just report them. (Pupil 2, age 15)*
>
> *You don't want someone that will put you in a bad path and get you in trouble. (Pupil 28, age 12–19)*

Experiences and understanding of supportive relationships and sexuality

There was mixed understanding amongst the pupils on the concepts of friendships, relationships, sexuality and sex. When asked about sexuality some pupils responded they were "not quite sure" or "don't really know", whilst for others, they were aware and knowledgeable of gender diversity. A few pupils shared personal experience of being transgender, gay or bi-sexual. Consent was generally understood amongst the pupils with reference to "permission" often used. The importance of respecting a person's response and the consequences of not doing so was appreciated and understood by most. Furthermore, the concept of knowing "what's right and wrong" featured across the narratives. This was not only in terms of consent but also regarding being vulnerable and the prevalence of abuse in relationships.

Well that is how you pretty much bring babies into the world. Create new people. (Pupil 3, age 13)
It's practically just like, relationship wise and well, just like, like, it's how to explain, but like, having a girlfriend, or a boyfriend. What I learned was like sexuality, like who you like too, like boys or girls and maybe trans, like all that, if you understand me. (Pupil 33, age 15)
Just making sure yes is yes, and no is no. So, yes is they want to do it, and no is, don't be touching them, don't be doing anything. Just have common sense. (Pupil 32, age 14)
It is important to know how a person will react and what they are used to and what they are not comfortable with. It is just important to know all this stuff because if you don't, it could go wrong, very wrong. (Pupil 2, age 15)
Sometimes in relationships you need to find the signs of red flags when abusive relationships and then you go to someone and tell them what your partner or friend or like anyone that's abusing you, or like children too. (Pupil 28, age 12–19)

Valuing the exchange of knowledge and information

It was very clear that the exchange of information relating to relationships and sexuality education from the educators and between their peers was appreciated by all. Whilst different modes of learning took place, classroom-based practical learning with teachers was the perceived preference amongst the pupils. For some, there was an element of embarrassment regarding some words and topics used, or at the thought of parents being involved. In general, however all pupils were prepared to talk openly and have discussions amongst their peers and with teaching staff. The value of the information being imparted was deemed important by the pupils as it was relevant to all stages of their lives from puberty to long term relationships, and associated legislation.

It's important to learn because if you don't know then you don't know what's happening to your body. (Pupil 23, age 12–19)
I'm bi so I like girls and boys. Yeah, so, it like helps me know what I like and what I am attracted to. (Pupil 28, age 12–19)
It is just interesting learning about sex education … it is just great to know all this stuff because it can come in useful. (Pupil 2, age 15)
I think it's very useful for life and going forward in relationships like what you are going to do when you're older and your own choices … I reckon it's so important because like, it can be too late and then a baby comes. Then practically your childhood's ruined because you have a baby and all your friends are going out to clubs or whatever, and you're sitting in the house minding a baby. (Pupil 33, age 15)

Discussion

Our findings provide new insights and understanding of how children and young people with intellectual disabilities have experienced relationships and sexuality education. It has evidenced that they want to know about the topic and see the value in learning about relationships and sexuality. Participants were enthusiastic and curious to learn more and were cognisant of the possible dangers around seeking information from the internet or social media. A systematic review on how people with disabilities used social media identified six themes including community, cyberbullying, self-esteem, self-determination, access to technology and accessibility [38]. Community was the largest reported theme and referred to people coming together to share common interests, needs, ideas or for the purpose of collaboration, support and identity development [38]. People with intellectual disabilities routinely utilised social media and social networking sites to stay in touch with friends, enjoying the experience. However, some have experienced bullying and exploitation [39]. Pupils in our study sought information about relationships and sexuality from both online and offline sources. Therefore, it is important that information provided is accurate, accessible and free of judgement to ensure children and young people remain safe and well informed.

The pupils valued positive friendships and sought peers who held similar interests. Attributes such as trustworthiness, politeness, being nice and helpful were all seen as important. As with their typically developing peers, children and young people with intellectual disabilities

desire belonging and friendship which often comes with a certain degree of conflict [40]. Our participants also made use of social media to keep in touch with school friends and family and were not averse to blocking contact if they were treated poorly. Friendships can provide emotional support, increases self-worth and well-being and are an important source of information [41]. In some cases, friendships among children and young people with intellectual disabilities can be difficult to maintain and develop and can be damaged by prejudice on the part of peers and others [42]. Therefore, RSE should provide information to children and young people with intellectual disabilities on how to negotiate, navigate, maintain and terminate friendships and how to identify the characteristics of good and poor relationships.

The concept of sexuality elicited a variety of responses from our participants. Some pupils were aware of the diverse expression of sexuality while others were unsure what this referred to. Research evidences that adults with intellectual disabilities want access to information about expression of their sexuality, rights and responsibilities, including protection from exploitation and abuse [15]. As adults with intellectual disabilities have identified this need, current educational provision is clearly inadequate leaving children and young people at greater risk of harm, exploitation and sexual abuse [28]. It is therefore important to have an open and honest discussion with children and young people about their sexuality to ensure they are well informed and can understand differences in the expression of human sexuality safely. This is particularly important in cases where children and young people with intellectual disabilities do not identify as heterosexual. There is currently limited support for people with intellectual disabilities who identify as lesbian, gay, bi-sexual or transgender [15, 43]. It was encouraging to identify that our participants recognise the concepts of consent and respect. This is positive, as research has evidenced that some adults with intellectual disabilities scored lower on a measure of consent and abuse than typically developing adolescents [44]. However, the authors suggest capacity to consent may undergo change and can be dependent on the young person's level of knowledge and situation [44]. The development of an RSE programme would have to place issues of consent to sexual intimacy at the centre and should seek to increase the knowledge of children and young people to support healthy and safe sexual decision-making and experiences.

The pupils in this study preferred to receive their information from teachers and saw them as a trustworthy source. While peers and parents were also discussed as sources of learning these interactions were thought to be less reliable and potentially more awkward or embarrassing. Delivery of RSE in special schools has experienced some challenges such as a lack of training for teachers and inadequate materials for use with pupils with intellectual disabilities [28]. While programmes have been developed for typically developing children and young people, no evidence-based programme has yet been developed specifically for the intellectually disabled pupils. Research has identified that people with intellectual disabilities want information about sexual health and have often had to acquire this knowledge through lived experience [45]. Delivering an evidence-based RSE resource at school is the preferred method of learning for our participants. However, it is important to keep parents and carers informed and apprised of RSE content delivery to ensure any conversations at home did not come as a surprise and any misunderstandings could be sensitively addressed.

Policy implications

Children and young people with intellectual disabilities have the right to education under Article 24 of the United Nations Convention on the Rights of Persons with Disabilities [10]. Article 24 states that people with disabilities should be enabled to learn life and social development skills to facilitate equal participation in education and their communities [10]. As such, the state has a legal requirement to provide education which meets the needs of people, including children, with intellectual disabilities. To support children and young people with intellectual disabilities to participate in their communities, educational policy makers should ensure the provision of good quality RSE which meets their needs, is evidence-based and rigorously tested. Not only should RSE be available to pupils with intellectual disabilities, in addition, content and teaching needs to be tailored to meet specific learning needs taking account of their developmental stages [3].

Our findings support this position and evidences that children and young people with intellectual disabilities want to learn about relationships and sexuality and see the benefit of acquiring this information. To enable this, there is a need to create and implement evidence-based programmes for pupils with intellectual disabilities in schools. Such programmes would have the benefit of being directly relevant to the needs and concerns of pupils and would address, in an easily accessible manner, RSE issues that affect them. Education policy makers should ensure that programmes are rigorously developed, tested, implemented and evaluated to allow children and young people with intellectual disabilities access to this important information.

RSE policy guidance is available for typically developing children and young people and is required for those with intellectual disabilities. Policy makers should co-design and co-produce RSE guidance with the range of key stakeholders including children and young people to

ensure the development of a fully compressive strategy. To be effective, RSE policy needs to set out the delivery context of RSE for children and young people with intellectual disabilities, taking account of age, set within cognitive ability level. RSE policy specific to the needs and concerns of children and young people with intellectual disabilities clearly setting out the broad areas that should be the focus of programmes to ensure consistency and allow for the impact and outcomes to be identified.

The current research has focused on pupils with intellectual disabilities in a special school setting. The findings and recommendations arising from the study offers a way forward to grow and build on the work currently taking place regarding RSE. It is therefore relevant to policy makers, professionals working with children and young people with intellectual disabilities in school settings and their families. The inclusion and participation of the parents and families of children and young people with intellectual disabilities are also key to the effective development and delivery of RSE. Through their participation in the current study, it is evident that children and young people with intellectual disabilities can and want to be included as the key consumers of RSE.

This is important as all children and young people, including children and young adults and adults with intellectual disabilities require information regarding relationships and sexuality. RSE information will differ to that provided to school aged children, however it applies equally across the lifespan and is lifelong. Therefore, appropriate educational provision regarding RSE should continue through day services to support and help ensure young adults with intellectual disabilities develop safe and fulfilling friendships and relationships after they leave school. This approach could also benefit older adults with intellectual disabilities who may not have received any tailored evidence-based RSE while at school specific to their needs and ability level.

Strengths and limitations

To our knowledge, this is the largest study to identify the voices of children and young people with intellectual disabilities regarding RSE. Many studies to date have focused on the perspectives of families and carers, adults with intellectual disabilities and professionals, omitting the views of children and young people. Therefore, the findings of the study provide an in-depth understanding of the experiences of pupils with intellectual disabilities in special school settings regarding RSE provision. Further, this study presents the views of pupils from across the UK and is not therefore limited to one single geographic region. This has increased the representativeness of our findings. However, many participants came from Northern Ireland, and no representation of non-verbal children and young people, which may have influenced the results and wider relevance. Our use of both semi-structured interviews and focus groups may also have influenced the findings. While there were practical considerations in using both approaches, for example, a focus group took up less classroom time, the different dynamics involved (group discussion versus one-to-one discussion) may have resulted in less detailed narratives from pupils involved in focus group interviews. This study did not include information of the level or grading of intellectual disability and therefore our findings may not be generalised more widely. Implementation of RSE curriculum requires careful planning to make it accessible for specific types and level of intellectual disability.

Conclusions

The findings from this study highlight the views and experiences of pupils with intellectual disabilities with regard to their learning about RSE. Undoubtedly, these children and young people want information about relationships, sexuality and sex, to increase their understanding and knowledge to help protect them as they move into adulthood and leave school. While special schools provide relationships and sexuality education, there is a requirement for a programme and resources specific to the needs of children and young people with intellectual disabilities to be developed and evaluated. Furthermore, the content requires to be personalised and tailored to their developmental stages. In addition, a programme should be developed to enable RSE to continue beyond school and be embedded in adult services.

Abbreviations

RSE	Relationships and sexuality education
SEND	Special educational needs and disabilities
UK	United Kingdom

Supplementary Information

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Supplementary Material 1: Interview guide

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Author contributions

M.B. and M.L. designed the study. F.M. collected the data. M.B., M.L., L.M., M.T., F.S. and F.M. analysed the data. M.B., M.L., L.M., M.T., F.S. and F.M. wrote the manuscript. All authors, M.B., M.L., L.M., M.T., F.S. and F.M. read and approved the final manuscript.

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Data availability
The data that support the findings of this study are not openly available and may be available from the corresponding author upon reasonable request.

Declarations

Ethics approval and consent to participate
Was granted by the Faculty of Medicine, Health and Life Sciences Research Ethics Committee (Ref: MHLS 19_19) on the 19/02/2020 at the lead authors institution. All participants were provided with an easy read study information sheet and consent form prior to participating in an interview. All gave written informed consent prior to the interview. Participants under the age of 16 in England, Northern Ireland and Wales, also had written consent from parents or carers.

Consent for publication
Not applicable.

Competing interests
The authors declare no competing interests.

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Publisher's note

IT'S MY LIFE - MAKING IT OUR REALITY

Best practice guidelines for health, social care and education practitioners regarding relationships and sexuality education programmes for children and young adults with intellectual disabilities

RESIDE

RELATIONSHIPS AND SEXUALITY IN INTELLECTUAL DISABILITY EDUCATION

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RESIDE

RELATIONSHIPS AND SEXUALITY IN INTELLECTUAL DISABILITY EDUCATION

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CONTENTS

EXECUTIVE SUMMARY

WHAT ARE THE ISSUES?

Children and young people with intellectual disabilities experience specific and distinct barriers regarding developing and sustaining relationships and in the expression of their sexuality. However, while some Relationships and Sexuality Education (RSE) programmes do exist for this population, it is unclear what content is currently being delivered in special schools and if and how it is evaluated. RSE programmes should be consistently evaluated to ensure they effectively meet the needs of children and young people with intellectual disabilities and address the concerns of parents.

WHAT DID WE DO?

A total of eight special schools across England, Northern Ireland (NI), Scotland, and Wales, participated in the study. In-depth qualitative and focus group interviews were undertaken including children and young people, parents, health, social care and education practitioners collectively referred to as 'professionals', who consented to participate. A total of 37 pupils with intellectual disabilities aged between 12 and 19 years participated in an individual or group interview. Semi-structured individual interviews took place with 11 parents of children and young people with intellectual disabilities, and seven with healthcare and other professionals. Two focus groups took place with nine healthcare and education professionals.

The findings and experiences of good practice and methods of programme delivery were used to develop best practice guidelines for professionals regarding RSE content and delivery to meet the needs of children and young adults with intellectual disabilities.

WHAT WE FOUND OUT?

- Children and young people with intellectual disabilities want education and information to develop their knowledge and understanding regarding friendships, relationships and the expression of their sexuality.

- Parents of children and young people with intellectual disabilities recognise the need for their children to have access to education that is tailored and specific to their individual needs.

- A range of professionals are involved in the development and delivery of RSE programmes, adopting creative teaching and learning approaches.

WHAT NEEDS TO HAPPEN NOW?

- The best practice guidelines should be used to enable health and other professionals to develop, implement and evaluate RSE programmes specific to the needs of children and young people with intellectual disabilities.

- All RSE programmes need to be developed and delivered around clearly defined learning aims, objectives and outcomes.

- A formal evaluation of the impact and outcomes achieved as a result of participation in a RSE programme should be undertaken.

RECOMMENDATIONS

The findings from the in-depth qualitative interviews and focus group interviews with pupils with intellectual disabilities, parents of children and young people with intellectual disabilities, and healthcare and other professionals informed eight main evidence-based recommendations:

RECOMMENDATION 1

A structured, evidence-based RSE programme needs to be developed, tested and implemented within special schools for children and young people with intellectual disabilities.

RECOMMENDATION 2

RSE programme development needs to be flexible and adaptable and delivered for all levels of intellectual disability, age and ability across special school settings.

RECOMMENDATION 3

Defined aims, objectives and outcome measures for the delivery of relationships and sexuality education need to be developed and implemented for RSE programmes.

RECOMMENDATION 4

Evaluation mechanisms before, during and after delivery need to be developed and integrated within all RSE programmes.

RECOMMENDATION 5

There is a need to develop and implement a support network for professionals involved in the development, delivery and evaluation of RSE programmes.

RECOMMENDATION 6

Longitudinal follow up studies are required to identify the impact and outcomes achieved through the delivery of RSE programmes.

RECOMMENDATION 7

Further research is required which adopts a lifespan approach on the RSE needs of adults with intellectual disability to ensure they have evidence-based information to make informed choices and decisions.

RECOMMENDATION 8

There is a need to scope and develop a RSE programme to address the specific needs of adults with intellectual disability living in the community.

DEFINITIONS

HIV

Human immunodeficiency virus

PROFESSIONALS

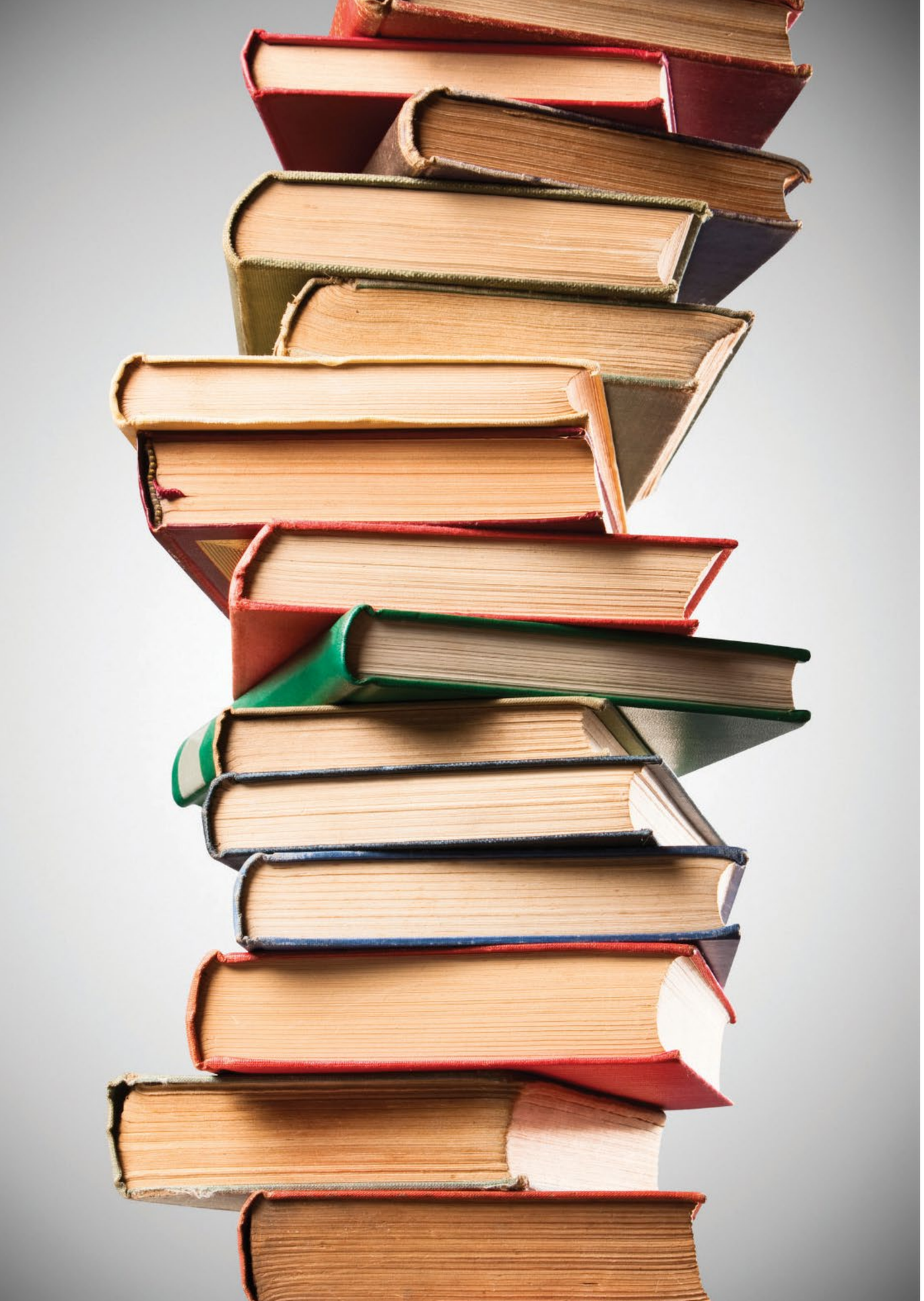
Health, social care and education practitioners for example, school nurses, teachers, teaching assistants, education managers.

RSE

Relationships and sexuality education

STIs

Sexually transmitted infections



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> “One size doesn’t fit all … you can’t roll out the same thing to everyone because it has to be person-centred really”.

INTRODUCTION AND CONTEXT

BACKGROUND

An intellectual disability refers to a significant impairment of general intellectual and adaptive functioning that originates in childhood (Cooper et al., 2014). Approximately 2.5% of the UK population have an intellectual disability, equating to some 1.5 million people. Of this there are 286,000 children - 180,000 boys, 106,000 girls - age 0-17 with an intellectual disability (Emerson & Hatton, 2008; Lenehan, 2017). The population of children and young people with intellectual disabilities is increasing and ageing, with more living into adulthood with a range of neurodevelopmental, physical, behavioural and mental health needs (Huang et al., 2016). The increase is due to improvements in neonatal intensive care and health care services and access to care and support (Jarjour, 2015). Children and young people with intellectual disabilities often have more complex support needs than other children to understand, learn and remember new information and skills. They may need additional support with everyday activities such as communicating, keeping safe and undertaking everyday tasks. Many will require specialist services at some point in their lives (Emerson & Hatton, 2008).

There have been significant policy changes and developments over recent decades regarding the education of children and young people with intellectual disabilities with moves to inclusive education (Buchner et al., 2021). Parents of children with intellectual disabilities may wish their child, where possible, to attend the same school as typically developing children. Some, due to their specific learning and support needs may attend a blend of mainstream and special education provision (Klang et al., 2020). For some children, particularly those with the most complex of education and support needs, full-time attendance at special education provision may be appropriate (Florian, 2019). Despite their additional needs, all children and young people with intellectual disabilities have the right to have their needs recognised and promoted, their voices heard and receive education, care and support to enable them to reach their full potential, set within the context of the United Nations Convention on the Rights of the Child (UNICEF, 1989). Despite these aspirations and the positive developments, children and young people with intellectual disabilities experience specific and distinct barriers regarding developing and sustaining relationships and in the expression of their sexuality.

Existing literature recognises the rights of people with intellectual disabilities to have fulfilling lives and to make their own life choices (Simpson et al., 2006; World Health Organisation, 2015). People with intellectual disabilities want friendships, meaningful relationships and some want intimacy (Box & Shaw, 2014). However, the expression of sexuality is an area where potential freedoms are often limited and restricted, compared to typically developing young people (Jahoda & Pownall, 2014). People with intellectual disabilities are often misperceived as being either asexual, hypersexual or sexually immature (McCann & Brown, 2018). Additionally, several studies have highlighted issues related to autonomy versus vulnerability, exploitation or risk of harm (Conder et al., 2015; Fisher et al., 2016). There is a need to develop the understanding of families and professionals in education, social care and health services that many people with mild and moderate intellectual disabilities are interested in and actively engage in sexual relationships (Brown & McCann, 2018; Frawley & Wilson, 2016). However, they may possess less knowledge about relationships and sexuality, display more inappropriate sexual behaviours and often do not understand the consequences of engaging in unprotected sex when compared to their typically developing peers (Ballan, 2012). Many practice unsafe sex, are less likely to use contraception, have an increased risk of having an unplanned pregnancy, and have greater exposure to the human immunodeficiency virus (HIV) and sexually transmitted infections (STIs), compared to typically developing young people (Jahoda & Pownall, 2014; McCarthy, 2014). Young people with intellectual disabilities who are sexually active are at greater risk of sexual abuse and exploitation. This contributes to the increased risk of mental health conditions such as anxiety, depression and low self-esteem. Some also experience difficulties in forming and maintaining relationships resulting in loneliness and social isolation (Baines et al., 2018; McDaniels & Fleming, 2016). Current research evidence indicates that young people with

intellectual disabilities may not have proper access to suitable relationships and sexuality education programmes (McCann & Brown, 2018). While some Relationships and Sexuality Education (RSE) programmes do exist for this population, most focus on knowledge acquisition regarding sexuality and sex, lacking a focus on healthy relationships, informed choices and decision-making (McDaniels & Fleming, 2016). Furthermore, potential RSE programmes should involve young people with intellectual disabilities, parents, and professionals involved in their education, care and support. However, despite these issues, there remains a definitive gap in the delivery of RSE programmes that specifically address relationships and sexual needs and concerns for this population (Brown & McCann, 2018).

Rationale

There is no evidence-based best practice guide for healthcare and other professionals regarding addressing the RSE needs of children and young people with intellectual disabilities. It is unclear what is currently being delivered in special schools and if what is delivered is taught and evaluated consistently and in a way that meets the needs of children and young people with intellectual disabilities whilst also addressing parental concerns. Therefore, limits in consistency of provision and delivery ultimately impacts on life choices and places the health of children and young people with intellectual disabilities at risk, and may increase their vulnerability to harm, abuse, sexually transmitted infections and unintended pregnancy. Healthcare and other professionals have important health education roles in meeting the needs of young people with intellectual disabilities, including those related to relationships and sexuality. They are therefore well placed to work with children and young people with intellectual disabilities and their parents to ensure that relationships and sexuality education needs are identified and effectively addressed.

This study therefore sought to identify the contributions of healthcare and other professionals in the provision of RSE programmes in exemplar schools in England, Northern Ireland (NI), Scotland and Wales. Key stakeholders, including children and young people with intellectual disabilities, parents, school and sexual health nurses, teachers and other professionals were involved to identify current provision and best practice to inform the development of this best practice guideline to inform content and delivery in the special school setting. This work has led to the development of best practice guidelines to inform practice and future RSE delivery.

ETHICAL CONSIDERATIONS

Ethical approval to conduct this research was received from the Faculty of Medicine, Health and Life Sciences Research Ethics Committee, Queen's University Belfast prior to commencing the study. An amendment to the original application was sought, and approved, to expand recruitment to include England and Wales, and allow for online participation.

Information on the study was provided by the research fellow to the gatekeeper on each site for distribution to pupils, parents and professionals. The gatekeeper shared details of those interested in participating with the researcher to arrange a qualitative semi-structured interview or focus group. In advance of interviews and focus groups taking place, all participants received an information sheet and returned a completed consent form. Parents/carers of pupils who expressed interest were also sent an information sheet and asked to complete a consent form.

DEVELOPMENT OF BEST EDUCATION PRACTICE GUIDANCE

AIM AND METHODS

The aim of the study was:

To develop best practice guidelines for intellectual disability and other nurses on relationships and sexuality education (RSE) for children and young people with intellectual disability.

A project advisory group was established comprising professionals involved in RSE programmes for children and young people with intellectual disability, who had an interest in the work. A total of eight special schools across England, Northern Ireland, Scotland, and Wales, were approached and invited to participate in the study. In each participating school, the principal or a designated teacher, acted as a gatekeeper to identify pupils, parents and professionals who would be willing to take part in interviews and focus groups. These individuals were then issued letters of invitation and information about the study. Members of the nursing profession were approached through existing contacts of the research team.

The research fellow liaised with the gatekeeper in each school to arrange interviews with the pupils. Interviews and focus groups with parents and professionals were organised by the researcher following direct contact with those who expressed an interest in participating.

In-depth, qualitative semi-structured interviews and focus group interviews took place with all participants who agreed to take part in the study. A series of open-ended questions were asked to identify current best practice in RSE provision.

What was the response?

During a period of 13 months from February 2022 to February 2023, 90 expressions of interest were received which comprised 47 pupils with intellectual disabilities and 16 parents. The remaining 27 responses were received from health, social care and education practitioners (for example, school nurses, teachers, teaching assistants, education managers) and will be collectively referred to as ‘professionals’ for the purpose of this report.

A total of 64 individuals subsequently participated in an interview or focus group. Figure 1 shows the geographic locations of expressions of interest across the United Kingdom. Table 1 shows the breakdown by group of those who participated. The remaining 26 who were unable to take part included 10 pupils who became ill, or parents did not provide consent; and 5 parents and 11 professionals who were contacted on a number of occasions and did not respond.

A total of 37 pupils with intellectual disabilities aged between 12 and 19 years participated in an interview with the research fellow. A Microsoft Teams online interview took place with 13, and face-to-face individual interviews took place with 4, some of whom also had a member of teaching staff present. Each interview lasted between 10 and 22 minutes. The remaining 20 pupils took part in two focus groups from one school consisting of an all-boys or all-girls group. Each focus group had a number of education staff present for additional support. The boys’ focus group had a total of 12 participants and lasted 34 minutes; while the girls’ focus group had a total of 8 participants and lasted 39 minutes.

Semi-structured individual interviews took place with 11 parents of children and young people with intellectual disabilities and 7 professionals. Each interview lasted between 14 and 51 minutes for parents, and 26 to 66 minutes for professionals. Interviews took place via Microsoft Teams, telephone, or in person in the school or parent’s home.

Two focus groups, facilitated by the researcher, with 5 teaching professionals in group one and 4 teaching,

nursing and management professionals in group two, took place online via Microsoft Teams and lasted 53 and 33 minutes respectively.

Conversations during all pupil, parent and professional interviews and focus groups explored:

- Experiences and understanding of relationships, sexuality and consent
- Experiences of RSE programmes
- Identifying topics for inclusion in an RSE programme
- Collecting examples of good practice and methods of delivery

All interviews and focus groups were audio recorded and transcribed verbatim by the research fellow. All identifiable information was removed and each participant was allocated a pseudonym.

Table 1: Participant groups across the United Kingdom

REGION	PUPILS	PARENTS	PROFESSIONALS	TOTAL
England	5	3	5	13
Northern Ireland	24	6	8	38
Scotland	5	0	1	6
Wales	3	2	2	7
TOTAL	37	11	16	64

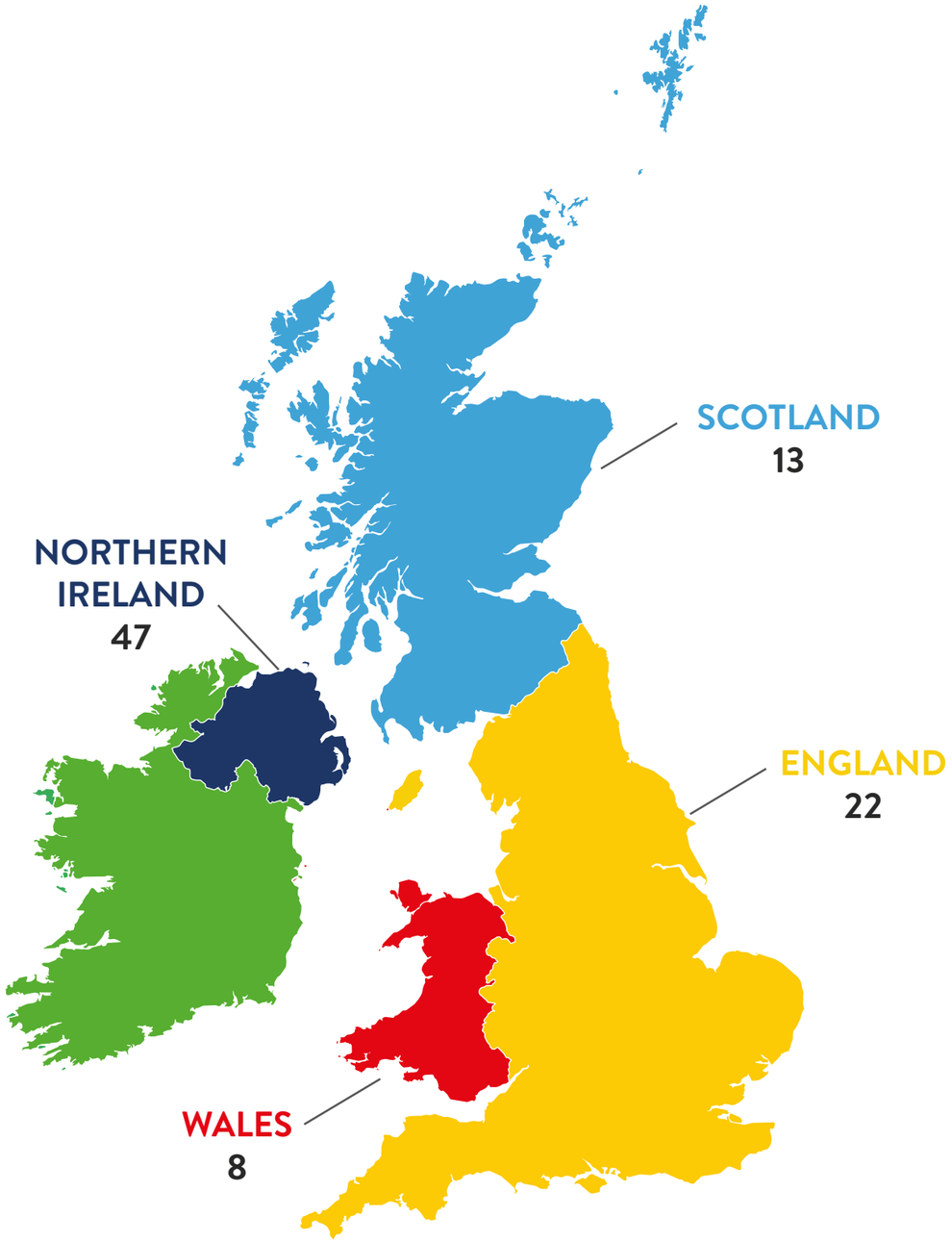

Figure 1: Distribution of expressions of interest across the United Kingdom

WHAT DID WE FIND

There was overall positivity from all participant groups that RSE should be taught to children and young people with intellectual disability. Participants felt that, like all young people, those with intellectual disability also have relationships and friendships and require knowledge and information to help them make better informed choices and decisions.

The data showed parents were supportive of their children learning about RSE rather than preventing or limiting it. However, we are aware that some parents might feel uncomfortable in broaching RSE topics with their children and acknowledge that those taking part in this research may be those who are in favour of RSE provision.

There was a clear rationale and context for teaching RSE to young people with intellectual disability. It was recognised that they have equal rights as children to lead a full and rewarding life, and should be provided with appropriate information relevant to their needs.

The importance of keeping safe and healthy was an important component and was reflected in the narratives of pupils, parents and professionals.

DATA ANALYSIS

All transcripts were read independently by the research team to gain an understanding of the participants' views and experiences and identify themes and sub-themes. Following this the transcripts were discussed collectively by the research team to identify and agree the final sub-themes and themes across and within the data. As a result of this process, three main themes with associated sub-themes (Table 2) were identified and described below.

Table 2: Themes and sub-themes relating to participants' experiences of RSE programmes

MAIN THEME	SUB THEMES
Initial Planning and Preparation	• Learning styles and learning needs • Age and ability • Communication
Delivery of RSE	• Delivery modes • Who delivers? • How is it delivered?
Evaluation of RSE	• Programme evaluation • When to deliver again?

> “It’s on the child’s level as well, which is really important. You’ve got to use the language and the actions that they understand”.

“They don’t talk about it, not enough, so, I think they should talk about it more … I think it is just a bit late to start it, because other schools do it in Year 8 and Year 9, and we’re doing it in Year 11”.

THEME 1: Initial Planning and Preparation

LEARNING STYLES AND LEARNING NEEDS

Parents and professionals were keen that young people with intellectual disabilities, irrespective of the child’s level of disability, should be afforded the same opportunity to learn about relationships and sexuality as typically developing children:

“You can’t go in and have a lesson with somebody like my [daughter] who is completely non-verbal and has a severe learning disability and give the same lesson to a child who will go home and say oh mammy guess what we were chatting about today. It has to be aimed at that child’s level”. Parent 3.

However, it was recognised that this brought challenges to delivering the topic with the general consensus that a specific tailored and accessible programme should be developed. In addition, the RSE programme should be tailored to suit the level of the child’s understanding:

“One size doesn’t fit all … you can’t roll out the same thing to everyone because it has to be person-centred really”. Professional 13.

Irrespective of the person’s level of intellectual disability, it was deemed important that a learning needs assessment would be conducted before any teaching was delivered on an individual basis or within a classroom setting:

“There needs to be that discretion or ability to make sure it’s individual to the individual nature of the child, young adult or person growing up”. Parent 5.

AGE AND ABILITY

There was an overwhelming agreement particularly amongst pupils and parents that RSE should be

introduced into the curriculum at an earlier age and stage and built upon over time, as developmental changes commence, particularly for girls as young as nine or ten years old, and curiosity increases:

"They don't talk about it, not enough, so, I think they should talk about it more ... I think it is just a bit late to start it, because other schools do it in Year 8 and Year 9, and we're doing it in Year 11". Pupil 33.

"I think it's essential that it is taught in school because these children have a lot of learning to do around this. It is something I would say should be started at a young age. Now when they are a young age, you are just talking very simple things. But I think it is something that has to progress with them". Parent 4.

"They should be taught at an earlier age because they forget that wee girls can take their period from an early age ... I am just glad that I was opened enough to notice that she was fully developed from she was about nine, ten, years old". Parent 8.

Other challenges highlighted particularly by professionals regarded pitching their teaching at the right level to make it accessible and relevant for the individual pupil. This became increasingly difficult when there was a mixed ability and understanding within the same group of pupils. It was considered important that the young people understood the "foundations" of the "complexities of friendships and relationships" before moving onto sexuality education and the safeguarding elements.

These challenges were also recognised by parents; however, they wanted their children to be taught about relationships and sexuality at the appropriate time as they were mindful they would develop into fully functioning and more independent adults irrespective of their age or level of intellectual disability:

"The mechanism for delivery is completely different depending on who you're working with, age range, ability wise, an important message". Professional 11.

"Whether it's done at a slightly later age range depends on the ability of that class. But it should still be delivered just as it is in a mainstream school because I don't understand why it's not. Maths is taught in all different schools, both special and mainstream. English is taught in mainstream and special, as is PA [physical activity]. So, is this not something that should also be taught because children with need will go on to be, they're not always going to be a child with additional needs, they will be an adult with additional needs". Parent 2.

COMMUNICATION

Professionals recognised the need to consider and incorporate individual communication styles and what would potentially work best for each pupil when preparing RSE programme content and delivery:

"It's very pupil led and everything is based around their sensory needs and their kind of regulation". Professional 1.

"It's on the child's level as well, which is really important. You've got to use the language and the actions that they understand". Professional 8.

In addition, the need for effective communication and a positive relationship with parents in the development, planning and preparation stage was recognised by many professionals as paramount:

"There's a certain relationship needs to be developed between parent and school that's conducive to the learning, again of the young person. Because anything that we do, we send home to the parents as well ... we believe that there's the triangle ... the individual, there's the parent care, and there's any other professional involved in their life ... young people need to be getting the consistent message". Professional 11.

To support teachers and maintain consistency and accuracy in the information being delivered, all parents clearly articulated their need to be kept informed. They did not want to be involved in programme delivery, rather they wished to be made aware of when the subject was being delivered to their children and the content and topics being taught:

"Talk to us, about what it is specifically that you're covering, because we can mirror that at home ... if you've got any resources, send them home ... and you have some activities, let us know what they are ... so that they're getting the same information from all of the people that they trust and that they can see that we're working together on it. And we're not confusing them because if they are learning in a very specific way at school about something and then we might come home and have different terminology or a different value or a different take on it and we're saying oh, actually, no, do it like this, then we are just further confusing the issue for them". Parent 1.

"I knew that Tuesday afternoons were likely to be a little bit bumpy and I knew that in the afternoon at home time, to kind of clear my work diary a little bit because my son might have needed to have offloaded. And that was really, really helpful". Parent 11.

Some professionals were proactive in the involvement of parents and had invited them to workshops held in the school to discuss and share information and details about the RSE programmes. This was viewed as an important part of any RSE programme delivery which needs to be incorporated and planned for from the outset:

"We have done at least two parent workshops where the parents have come in and we have explained to them about our programme and about the barriers and obviously trying to allay the parents fears and anxieties about teaching sex education to their really special child and just trying to get it across, that we are not encouraging them to go out and have sex, we are not encouraging them to be sexualised. But that is a journey, and just in my experience from A to where we are now, B, all those years later, we have come miles and miles". Professional 6.

Some parents were apprehensive about the in-depth details and had no desire to be involved in the delivery of the programme, whilst another parent was keen to be involved on some level:

"I don't know if I would feel comfortable with all the detail. I do think it's better for him [son] being taught by a teacher because he associates the teacher with learning. Yeah, but I would like him to know that he could come and speak to me about things, which I don't think he ever would, or ever will to be honest, because he sees me as mummy, and that's not something that you talk about with your mummy". Parent 7.

"I would be fully on board with it, and I would want to be there, participating, be in the room when they are doing the lesson so that I can see what they are teaching [daughter] so that I can take that home and teach her the same thing. I think we all need to be on the same level when it comes to that, definitely. Because school can't teach them one thing and then me teach them something completely different". Parent 3.

“Feel very safe like because I know the safety of online safety, so if something happens, then I know what to do. I need to block the person”.

“You can’t go in and have a lesson with somebody like my [daughter] who is completely non-verbal and has a severe learning disability and give the same lesson to a child who will go home and say oh mammy guess what we were chatting”.

“We learned so much from [teacher] and she will keep us safe no matter what and she makes us happy about it. She will let us be happy and enjoy it … It’s about keeping you safe. It’s about being aware of the world out there because my mum said there’s some bad people that might make you feel uncomfortable”.

“There needs to be that discretion or ability to make sure it’s individual to the individual nature of the child, young adult or person growing up”.

RESIDE

RELATIONSHIPS AND SEXUALITY IN INTELLECTUAL DISABILITY EDUCATION

“I felt like it was a good course and it kind of taught you what’s right and what’s wrong”.

THEME 2: Delivery of Relationships and Sexuality Education

DELIVERY MODES

The setting and environment in which RSE was delivered was mainly in a school classroom. Within this context, in addition to learning in a whole group or classroom, there were alternative modes of delivery which included small group work and gender specific delivery to enable learning to take place at an appropriate pace and level of understanding:

“We try to have boys and girls together, rather than separate boys’ and girls’ groups, and any more personal questions that either gender wants, [female learning support assistant] will deal with the girls and I’ll deal with the boys. Such as periods, and masturbation with the boys, et cetera. So, separate that, otherwise we try and keep it all as neutral gender groups and have everyone together”. Professional 2.

Delivery on a one-to-one basis was also used on occasion, either for initial education on a specific topic or as a follow-up, to enable learning to take place at an individual's pace and level of understanding. The time allocated for each lesson was important recognising that flexibility was required to enable discussions with the pupils to come to a natural end rather than having to stop when the 'bell rings', which could lead to unanswered questions and increased anxiety. Novel approaches were facilitated to overcome this:

"I can rob from science and then when I am finished this is when I can finish the RSE, then I can use the RSE time to go back to science ... it works very well". Professional 15.

Interaction with peers and internet searches are frequently used as a mode of learning for neurotypical young people, and there was evidence that some pupils in this study were searching the internet and also asked friends for information to quell their curiosity:

"I get my information from online, [teacher], or anyone else willing to teach me ... I learn from other people". Pupil 2, age 15.

"I learned about like proper consent from YouTube videos". Pupil 13, age 17.

Whilst the pupils generally felt safe using social media and accessing the internet, there were concerns from parents and professionals as to inherent risks and potential danger of the internet and social media, including accessing unreliable and inaccurate information and being a potential target of exploitation by hint of their intellectual disability:

"Feel very safe like because I know the safety of online safety, so if something happens, then I know what to do. I need to block the person". Pupil 9, age 13.

"We had a horrific experience with an online predator ... you have all the parental controls, every time I think about it, it just makes my head explode ... we contacted the police, and it was all sorted out. It was all dealt with very, very quickly, but it was absolutely terrifying. It was awful, just what could have happened". Parent 4.

"For my son a lot of his learning will come from YouTube and things like that, which is always my worry because there's so much rubbish on there. And although we've restricted it, it doesn't matter because you still get some really awful things that come through". Parent 11.

"The random, silly things that you and I might google, and some of our people can't access the internet. Or when they do access the internet, they get into all sorts of messes". Professional 16.

WHO DELIVERS?

There was an eclectic mix of educators delivering RSE to the young people. Primarily this involved teachers and teaching assistants from within the school who had varying levels of knowledge and expertise in the subject. To assist with the delivery in schools, external educators were occasionally engaged. These ranged from school nurses and social workers from local Health and Social Care services to trainers from independent agencies specialising in relationships and sexuality education:

"There's a number of teachers I can think of that absolutely are terrified whenever I come in and they just don't want to be in the classroom, or they go out giggling ... because they can't cope with it. So, how are the pupils supposed to be engaging if they see their teachers going on like that ... and then they're [pupils] telling the teachers to wise up. They're saying it's nothing to be embarrassed about, wise up". Professional 12.

Irrespective of who delivered, the need to set the context and build rapport with the young people was vital and was especially important when an outsider was coming in to meet the young people and deliver topics:

"They came in the first time, and they just introduced themselves and they spent a bit of time just talking about something non-related to sexual education, talking about preferred programmes or whatever. We introduced that individual and they were able to just develop a bit of a relationship initially, and then we think it wasn't until week two or week three that we actually started to roll out a wee bit of education. I think in terms of that, but that's a very difficult thing to be able to do and spend that time for every individual and the difference between a specialist service and if you're going to roll this out in educational services is quite hard in schools". Professional 13.

There was a consensus among the professionals that collaboration and partnership with parents and families was vital to successful delivery and reinforcement of content at home which was articulated well by one parent:

"I think more than other curriculum areas, that splits very much into a parent responsibility and a teacher responsibility. Teacher responsibility is about the knowledge transmission to the individual student, child. The parent responsibility is the sensitisation of that knowledge to their individual child". Parent 6.

Parents were also proactive in teaching their children especially where the school had not yet introduced a topic and they considered the information was necessary, for example regarding menstruation:

"Slowly I sort of slipped wee things in to her. Told her, showed her what a sanitary towel was. Told her how to use it". Parent 8.

"Coming up to her period, how I got her ready for that is I would have started putting wee pads on her and got her used to having the panty liners on her ... when I would have been on my period, I would have brought her into the bathroom, and I would have showed her this is completely normal ... I had no bother with her when the periods arrived because I had that all put in place before ... it wasn't a shock to her". Parent 3.

However, parents recognised that not all would be confident or feel comfortable talking to their child about RSE:

"It would be something a lot of parents would have to take a back seat. Cause the same as any other child, there's a level of embarrassment ... or there's certainly likely to be at least with some children. You don't want your parents to be involved ... when you are learning about that kind of thing". Parent 10.

Irrespective of who delivered RSE there was evidence of embarrassment and awkwardness experienced by all pupils, parents and professionals:

"I just don't like talking about it". Pupil 5, age 14.

"Some of the words I didn't like out of it. So, I don't really say the words I don't like ... Just freezes me out if I say them". Pupil 31, age 14.

"A lot of the work that I'm doing with my son is that these are not things to be embarrassed or ashamed of, but it's about there is a time and a place. And I think this is where we struggle a bit because they don't really talk about that in school and that would be really, really helpful. It's that extra layer of those unwritten rules that my child doesn't understand. So, it's not about making them a secret, but it's about recognising when it would be ok to have those conversations and that is tricky". Parent 11.

"Some of the older ones [pupils] who are more aware in the class find it quite embarrassing ... and it's making them feel comfortable so that they can be really open to what we're going to be learning". Professional 5.

HOW IS IT DELIVERED?

In addition to traditional classroom-based approaches such as PowerPoint and group discussions, professionals were creative in their use of resources when delivering RSE and included activities such as drama, photographs, and worksheets. Parents were equally creative in how they delivered information to their child and at times used opportunistic life experiences to introduce or build on certain topics:

"I think a bit of drama helps a long way as well and keeping it very informal. And it's not me standing at the front of the board, going through slide and slide and slide". Professional 14.

"Trying every which way you can until it finally works ... discussion and talking and talking and talking and let them talk and listen to each other, and doing it practically". Professional 6.

"Sometimes it is about creating those opportunities when they happen ... incidental learning is a really big part of it. So sometimes it's about developing conversations and being led by him [son]". Parent 11.

Visual tools and practical activities such as lifelike dolls, condoms, sanitary towels and photos were often used by parents and professionals as this was deemed to be more engaging and significantly increased understanding:

"There is no point just talking to them about it, it has to be visual and it has to be so simple and factual and it's nothing that you have to understand this to do this. It doesn't matter about that, this is right, this is not right, this is what happens, this is what we do ... don't tell them what not to do, tell them what they have to do". Parent 4.

"Visual and practical definitely, because that's a good focus for our pupils. Anything like hands on, things that they can see is a lot better for their learning needs". Professional 7.

Social stories based on real life scenarios were also considered important aspects of delivery and discussed within groups, as well as using books designed specifically for children and young people with intellectual disabilities:

"Social stories or visual and light touch introduction, and then maybe reminders and sort of encouragement after it". Parent 5.

"I got a book on Amazon about what's happening to Tom and what's happening to, I forget, it's the girl book, and it's very descriptive in it, a lot of visuals for my autistic kids. And there was giggles and laughs but I want to be extremely open". Parent 9.

"I think the books Beyond Words stuff through Barry Carpenter has been good because there's no actual written words in the books. There's a story and the pupils are telling that story and they're empathising and they're sharing into that". Professional 4.

Additionally, practical workbooks and word searches were useful teaching resources although the time involved in preparing them was immense:

"The booklets are made taking into account the pupils special needs and for each of the tasks that they have to do, there's two or three different ways of doing it. It helps cater for kind of different learning styles, kinaesthetic learners like to do a cut and stick maybe, visual learners will maybe perhaps like to copy something across, or things like this ... it took a lot of work at home as well but it's worth doing". Professional 15.

Across pupils' narratives there was a preference for a visual and practical approaches in the delivery of RSE with opportunity provided to interact and discuss topics with their peers and teachers:

"I would rather start with the video". Pupil 10, age 19.

"Working together ... trying to figure out the problems on each sheet". Pupil 20, age 12-19.

"Putting yourself in the deep end and just kind of going for it". Pupil 32, age 14.

Overall, the pupils were accepting and appreciative of those who educated them, and valued the information they were being given:

"It is just interesting learning about sex education ... it is just great to know all this stuff because it can come in useful". Pupil 2, age 15.

"We learned so much from [teacher] and she will keep us safe no matter what and she makes us happy about it. She will let us be happy and enjoy it ... It's about keeping you safe. It's about being aware of the world out there because my mum said there's some bad people that might make you feel uncomfortable". Pupil 25, age 12-19.

"I felt like it was a good course and it kind of taught you what's right and what's wrong". Pupil 32, age 14.

“Visual and practical definitely, because that’s a good focus for our pupils. Anything like hands on, things that they can see is a lot better for their learning needs”.

“You still need that education and what might be relevant to somebody when they leave school, mightn’t be relevant to them five, six years down the line, so the education needs to be continued and the programmes need to be run”.

THEME 3: Evaluation of Relationships and Sexuality Education

PROGRAMME EVALUATION

Although considerable effort went into the initial planning and preparation of relationships and sexuality education, there was little evidence of formal evaluation taking place of the programme content or delivery. One teacher had taken the initiative and sought feedback on the RSE resources they had prepared for the pupils, from an external healthcare professional and some internal teaching staff which reassured them:

“It wasn’t like I just went off and did my own thing. I sort of did it and had sort of two internal people seeing what I was doing and then an external person because it is always good to have input from others”. Professional 15.

Evaluation and extent of learning were not routinely built into RSE programmes. However, the professionals were mindful that the content and delivery had to be effective and wanted to ensure the young people understood the information being given:

“It’s those kind of lower end that we are just going, is this an effective programme, how can we make this better for them”. Professional 4.

During the interviews and group discussions some pupils provided positive feedback which on occasion was directly aimed at the teacher or classroom assistant who was also in the room with them:

“We learned it from our best teacher ever … I was happy with [teacher] telling me because it made me more knowledgeable on it”. Pupil 28, age 12-19.

WHEN TO DELIVER AGAIN?

The amount of time allocated to RSE, and the age it was taught differed between each school. This was dependant on the preference of the school and the teacher assigned to deliver the subject; no standard approach was apparent. In some schools there was a 'one-off' programme of delivery, whilst in others it was delivered over several years, with each year reinforcing and building on the previous learning:

"Generally those first couple of sessions are like ease in sessions. Like something that's not too much for them to handle initially. So, they get comfortable and then you can start to explore those kind of deeper things a little bit, but definitely initially for those first couple of years we just talk about it in their own sex, but maybe they're learning about the other body, but they're not learning it with them there. And then they've got a bit of confidence by the time they hit that kind of older age group". Professional 4.

A resounding message that came through the narratives of the pupils, parents and professionals, was that teaching of RSE should not stop for young people with intellectual disabilities when they leave school. Rather, it should continue and be incorporated into Adult Services as it is only when these young people are experiencing the different situations as they grow older, that the learning has more meaning and impact:

"It shouldn't really stop there [leaving school] because there might be more stuff that school doesn't teach you that you should know". Pupil 31, age 14.

"For our children who don't necessarily follow a chronological learning path, for things like that to suddenly stop and fall off a cliff once they've left a full time, you know at 19, once they leave full time school situation, is doing them a disservice ... it's something that should be there for whatever it is that they're doing, whether it's a college, or vocational, or some other kind of care facility, after school, it should be a constant thread ... it's one of the most valuable things that is going to help them go forward in their life ... to kind of just fall by the wayside once they leave the school building, just really does them a disservice". Parent 1.

"You still need that education and what might be relevant to somebody when they leave school, mightn't be relevant to them five, six years down the line, so the education needs to be continued and the programmes need to be run". Professional 12.

> **“We learned it from our best teacher ever … I was happy with [teacher] telling me because it made me more knowledgeable on it”.**

OVERVIEW OF FINDINGS

The qualitative interviews with pupils, parents and professionals from across the four countries of the United Kingdom revealed the importance and value of teaching RSE in special education schools.

Our UK-wide qualitative study showed that the young people already possess some knowledge and understanding and want more information on friendships, sex, contraceptive use, and abusive relationships while parents were concerned about safety both in-person and online, the importance of respecting boundaries and consent. Both the young people and parents want to learn about relationships and mental health.

It was deemed important by the educators to ensure that learning had taken place before moving on to the next topic within a RSE programme. At times this required information to be repeated with more explanation or in accessible terms, or a pause placed on the programme to enable the pupils to process the information received. The young people were keen to learn about relationships and sexuality and embraced the many different delivery approaches utilised. They learned at a level and pace conducive to their needs which subsequently made them feel valued as young persons:

"I really thought it was useful to learn about it [RSE] ... I think it's very useful for life and going forward in relationships like what you are going to do when you're older and your own choices". Pupil 33, age 15.

"I reckon it's [RSE] so important because like, it can be too late and then a baby comes. Then practically your childhood's ruined because you have a baby and all your friends are going out to clubs or whatever, and you're sitting in the house minding a baby". Pupil 33, age 15.

RSE PROGRAMME MAP – WHAT TO DELIVER

The aim of the RSE Programme Map is to provide the professionals delivering the education with guidance and inspiration to assist them in the development and delivery of comprehensive relationships and sexuality education for all pupils within their remit.

The suggested content of the RSE Programme Map was identified through analysis of the data from the study participants which pupils, parents and professionals identified as the most important to include. These are grouped as falling under one of three themes: relationship; sexual; and 'cross-cutting'. Each theme is considered an interlinking piece of a jigsaw, with one informing the other, as shown in Figure 2:

RSE JIGSAW

RELATIONSHIP THEMES

FRIENDS FRIENDSHIP FAMILY PROFESSIONALS

- Types of friends
- Having friends - what is a good friend?
- Keeping friends
- Maintaining friendships
- When things go wrong
- Online safety, friendships and bullying
- Social influences and social media

CROSS-CUTTING THEMES

- Boundaries
- Emotional well-being
- Trust
- Physical health and well-being
- Respect
- Consent
- Capacity
- Age
- Ability level of ID
- Personal safety, safe behaviours and disclosure
- Exploitation, abuse and harm

SEXUAL THEMES

- Puberty
- Body parts and functions
- Sexual health and well-being
- Contraception, menstruation
- Pregnancy
- Masturbation
- LGBTQ+ and sexuality
- STIs
- Individual health and well-being

Figure 2: RSE Jigsaw Programme Map

Clearly defined learning aims, objectives and outcomes for the programme and each session within should be articulated at the outset.

> “The mechanism for delivery is completely different depending on who you’re working with, age range, ability wise, an important message”.

USEFUL RESOURCES

AMAZE
An online platform to provide sexual health education to children and young people, educators, health care providers, parents and guardians, mainly through the use of videos.
https://amaze.org

BARRY CARPENTER
https://barrycarpentereducation.com/category/research-2/

BODYSENSE INSTRUCTIONAL DOLLS
Three dolls to assist teaching sexual health education to students with intellectual disabilities.
Two of the dolls are anatomically correct adult dolls. To teach about the human body, hygiene and social interactions. The third doll has female genitalia and internal reproductive organs to teach anatomy, menstruation, hygiene, masturbation and reproduction.
http://bodysense.org.uk/wordpress/

BOOKS BEYOND WORDS
https://booksbeyondwords.co.uk

CCEA (Council for the Curriculum, Examinations and Assessment), Northern Ireland
Relationships and Sexuality Education
https://ccea.org.uk/learning-resources/relationships-and-sexuality-education-rse

CENTRAL SEXUAL HEALTH
NHS Forth Valley's website which provides additional support needs resources for use by a range of professionals.
https://centralsexualhealth.org/professionals/learning-disabilities/

CHALLENGING BEHAVIOUR FOUNDATION
https://www.challengingbehaviour.org.uk

CHANGE PEOPLE UK
A range of accessible resources for people with intellectual disabilities are available to buy on friendships, relationships, sexuality, LGBTQ, sex, safe sex, contraception, masturbation, pregnancy, parenting and sexual abuse.
https://www.changepeople.org/shop/products

CIRCLES SOCIAL SKILLS UTILITY ™
An app that simplifies sexuality by teaching about social relationships, intimacy and boundaries.
A pilot study found an improvement in user's understanding of social boundaries after using the app, particularly where physical contact should be minimal or not at all (Faught et al., 2020).
https://www.circlesapp.com/

Useful Resources contd. over/

USEFUL RESOURCES contd.

COMMON YOUTH
https://commonyouth.com

DEPARTMENT FOR EDUCATION IN ENGLAND
Support and training materials for schools to help train teachers on relationships, sex and health education.
https://www.gov.uk/guidance/teaching-about-relationships-sex-and-health#train-teachers-on-relationships-sex-and-health-education

DOWN'S SYNDROME ASSOCIATION
https://www.downs-syndrome.org.uk/about-downs-syndrome/lifes-journey/relationships-and-sex-education/

DR RANJ SINGH
How to Grow Up and Feel Amazing! The No Worries Guide for Boys
In this book Dr Ranj explains everything you ever wanted to know about puberty - plus lots more.

ELIZABETH SCHMIDT RESOURCES
https://ekschmidt.com/resources/

FAMILY PLANNING ASSOCIATION
Useful RSE information and resources.
https://www.fpa.org.uk/our-views/

FUMBLE
Your handy guide to sex.
https://fumble.org.uk

INFORMING CHOICES NI
Deliver Relationships and Sexuality Education (RSE) programmes.
https://informingchoicesni.org/education

JIGSAW
Teaching resources to help teachers confidently teach a well-being curriculum.
https://jigsawpshe.com/home

JUST THE TWO OF US
Big questions and short answers on sex, Down Syndrome, and sexuality.
https://justthetwoofus.org/?_ga=2.185697260.45255485.1676291197-2011108130.1676291197#toggle-id-15-closed

KEEPING CHILDREN AND YOUNG PEOPLE SAFE:
An Online Safety Strategy for Northern Ireland 2020-2025
https://www.health-ni.gov.uk/sites/default/files/publications/health/online-safety-strategy.pdf

MENCAP
Advice and support about sexuality and relationships for those with a learning disability.
https://www.mencap.org.uk/advice-and-support/relationships-and-sex

MIDDLETOWN CENTRE FOR AUTISM
Designs and delivers training programmes cognisant of the needs of parents, education professionals and those who traverse these groupings.
https://www.middletownautism.com

NSPCC
PANTS resources for schools and teachers.
https://learning.nspcc.org.uk/research-resources/schools/pants-teaching

PUBERTY AND SEXUALITY FOR CHILDREN AND YOUNG PEOPLE WITH A LEARNING DISABILITY (NHS, 2009).
A sexual health teaching pack for children and young people with disabilities aged 9-18 years including children with severe intellectual disabilities.
https://s3-eu-west-1.amazonaws.com/leedssexualhealth.com/downloads/Puberty-Sexuality-Pack.pdf

RAPE CRISIS SCOTLAND
Useful resources on sexual violence for young people.
https://www.rapecrisisscotland.org.uk/resources/?cat=3

RSHP (Relationships, Sexual Health and Parenthood)
The RSHP resource has been developed by a partnership of local authorities and health boards, with advice from Education Scotland and the Scottish Government. The resource can be used in early learning settings, schools, colleges and community-based learning. It is organised to sit within Curriculum for Excellence.
A network can be joined and subscription includes being kept informed of any developments in the delivery of RSHP education.
https://rshp.scot

SANCTUARY FILM, BLUE TEAPOT COMPANY, GALWAY, IRELAND
A film made with actors and advocates with intellectual disabilities to highlight relationships and sexuality.
http://blueteapot.ie/our_performances/sanctuary-film/

Useful Resources contd. over/

USEFUL RESOURCES contd.

SEX AND THE 3R'S:
Rights, Risks and Responsibilities: A sex education pack for working with people with learning disabilities
A resource that offers a framework for professionals to facilitate sexual health education to adults with intellectual disabilities that is inclusive of LGBTQ. Possible issues are identified, as well as suggestions on how to work around them. The topics include consent, safer sex, sexting, pornography and sexual abuse.
https://www.pavpub.com/learning-disability/sexual-health/sex-and-the-3-rs-rights-risks-and-responsibilities

SEXUALITY AND INTELLECTUAL DISABILITY:
A Guide for Professionals
A book on gender and sexuality for professionals working in the intellectual disability sector. Provides guidance and toolboxes on dating, sex education and LGBTQ inclusion.
https://www.routledge.com/Sexuality-and-Intellectual-Disabilities-A-Guide-for-Professionals/Triska/p/book/9781138231023

SHEPHERD SCHOOL, NOTTINGHAM, UK
A video of best practice showing the delivery of a sexual health education programme to young people with intellectual disabilities.
https://online.clickview.co.uk/exchange/channels/32366675/teachers-tv/videos/36769760/sex-and-relationship-education

SUPPORTED LOVING UK
A website advocating for the rights of people with intellectual disabilities to have relationships and provides a range of resources for people with intellectual disabilities, parents and staff.
https://www.choicesupport.org.uk/about-us/what-we-do/supported-loving

TALKABOUT
A structured programme for teaching and measuring social skills. It is a whole scheme of work which helps assess, teach and measure work easily.
http://alexkelly.biz/alexs-work-and-talkabout/

THE CENTER FOR PARENT INFORMATION AND RESOURCES
A website with a range of sexual health education resources for educators to use with children and adults with disabilities. This includes sexual development, sexuality, dating, healthy relationships, sexual self-advocacy, and information for parents and resources for specific disabilities.
https://www.parentcenterhub.org/sexed/

THINGS ELLIE LIKES AND THINGS TOM LIKES
Accessible books about sexuality, puberty and masturbation for boys and girls, and young men and women, with autism and related conditions.
https://uk.jkp.com/products/whats-happening-to-ellie?_pos=2&_sid=204e978de&_ss=r

TODD PARR
It's Okay to be Different.
https://www.toddparr.com/todd-parr/todd-parr-the-traveling-its-okay-to-be-different-tour/

FINAL CONCLUSION AND RECOMMENDATIONS

What is evident from the wider international research literature and the findings from our study is that children and young people with intellectual disabilities want education and information to develop their knowledge and understanding regarding friendships, relationships and the expression of their sexuality.

Parents of children and young people with intellectual disabilities recognise the need for their children to have access to education that is tailored and specific to their individual needs. They have concerns about potential exploitation and targeting by other young people and potential predators. Parents recognise that education and information is empowering for their children and they want to be involved and informed about the content of RSE programmes, what is being taught and when.

A range of professionals are currently proactively involved locally in the development and delivery of RSE programmes, adopting creative teaching and learning approaches. There is a need for formal evaluation of the impact and outcomes achieved as a result of participation in a RSE programme. There is currently little formal evidence that the children and young people can and do generalise their learning more effectively in different situations.

There is also limited evidence of the long-term outcomes achieved on issues such as forming and maintaining friendships, forming and developing relationships, consent and decision making, unplanned pregnancy, reduction in sexually transmitted infections and reduction in safeguarding concerns and exploitation.

Therefore, arising from the findings from our study a number of evidence-informed recommendations are made:

RECOMMENDATION 1

A structured, evidence-based RSE programme needs to be developed, tested and implemented within special schools for children and young people with intellectual disabilities.

RECOMMENDATION 2

RSE programme development needs to be flexible and adaptable and delivered for all levels of intellectual disability, age and ability across special school settings.

RECOMMENDATION 3

Defined aims, objectives and outcome measures for the delivery of relationships and sexuality education need to be developed and implemented for RSE programmes.

RECOMMENDATION 4

Evaluation mechanisms before, during and after delivery need to be developed and integrated within all RSE programmes.

RECOMMENDATION 5

There is a need to develop and implement a support network for professionals involved in the development, delivery and evaluation of RSE programmes.

RECOMMENDATION 6

Longitudinal follow up studies are required to identify the impact and outcomes achieved through the delivery of RSE programmes.

RECOMMENDATION 7

Further research is required which adopts a lifespan approach on the RSE needs of adults with intellectual disability to ensure they have evidence-based information to make informed choices and decisions.

RECOMMENDATION 8

There is a need to scope and develop a RSE programme to address the specific needs of adults with intellectual disability living in the community.

PROJECT DISSEMINATION

The findings of the study will be shared with the participating schools and a range of other organisations across the United Kingdom. Dissemination of findings will also take place via local and international events and publications including:

- An event in Northern Ireland
- Visits to schools
- Pupil webinar
- Journals

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“I really thought it was useful to learn about it [RSE] … I think it’s very useful for life and going forward in relationships like what you are going to do when you’re older and your own choices”.

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Review

The Design, Content and Delivery of Relationship and Sexuality Education Programmes for People with Intellectual Disabilities: A Systematic Review of the International Evidence

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Abstract: There is growing empirical evidence regarding the relationship and sexuality experiences and needs of children, young people and adults with intellectual disabilities. A total of twelve papers met the inclusion criteria regarding relationship and sexuality education (RSE) programmes specific to the needs of this population. The preferred reporting items for systematic reviews and meta-analyses (PRISMA) guidelines were followed and quality appraisal undertaken. The four themes identified were principles informing RSE programme development, design and content of RSE programmes, delivery of RSE programmes and evaluation of RSE programmes. The discussion presents areas that need to be addressed to ensure that people with intellectual disabilities, their families, carers and professionals are fully involved in the design and delivery of RSE programmes. Further research is required to identify the impact of the programmes and the sustained outcomes achieved. Recommendations are made regarding the activities required to enable the development of evidence-based and person-centred approaches to relationship and sexuality programmes.

Keywords: intimate relationships; sexuality; programme content; programme delivery; intellectual disabilities

1. Introduction

Sexual expression takes many forms and contributes significantly to an individual's health and wellbeing. The World Health Organization (WHO) highlighted in 2015 that the expression of sexuality is a fundamental human right and is multifaceted. The expression of sexuality includes safe and pleasurable sexual experiences free from discrimination, violence and coercion [1]. Internationally, there is an increased focus on improving health and developing ways of addressing health inequalities [2,3]. Health promotion and health education is advocated as a means to enable individuals and communities to make improvements in general health [4,5]. In order to be effective, such programmes designed to effect change in behaviour and attitudes need to be informed by recognized theoretical and behaviour change models [6]. Specifically, in relation to sexual health, the importance of sexual health improvement and prevention activities are recommended [7,8]. From a sexual health perspective, there has been increased attention on issues including sexual transmitted infections (STIs) [9], HIV and AIDS [10], youth pregnancy [11], contraception [12] and gender-based violence [13]. For children and young people, relationship and sexuality education (RSE) programmes have been developed to address these concerns for the purpose of providing knowledge and information to ultimately lead to

a satisfying and fulfilling adult life [14,15]. RSE programmes for typically developing children and young people aim to provide knowledge and skills regarding the development and maintenance of healthy intimate relationships. A recent systematic review of the content and delivery of relationship skills education programmes identified that most were designed to be delivered in a school setting by a class teacher. The review also highlighted that the programmes broadly focused on the interpersonal dimensions of relationships [16]. To this end, RSE programmes enable people to make informed decisions about their future relationships, develop resilience and know where to access help and support when necessary [17]. To achieve this objective, many countries have established structured RSE programmes that are embedded within the school curriculum that is intended to be inclusive of all young people [18–20].

An intellectual disability (ID) describes limitations in intellectual functioning which occurs before, during or shortly after birth and is life-long. An ID affects intellectual functioning and is referred to as a spectrum condition involving mild, moderate, severe and profound cognitive impairment. Intellectual functioning such as learning, problem-solving and judgement can be impaired as well as limitations in adaptive functioning in areas such as self-care and communication [21]. From a rights and quality of life perspective, there have been significant developments in the care and support of children and adults with intellectual disabilities (ID) over the past decades from predominately institutional to community focused care and support [22]. The primary policy intention being to enable children and adults with ID to develop more autonomy and make informed decisions about key aspects of their lives [23]. As with the typically developing, people with ID want meaningful relationships and desire sexual intimacy and to be sexually active [24]. As young adults with ID transition from child to adult services tensions are evident regarding the expression of their sexuality due to concerns regarding the risks associated with exploitation versus the right to experience relationships and intimacy [25,26]. However, concerns exist around an individual's lack of knowledge about relationships and appropriate sexual behaviours [27]. There may also be limited awareness of the potential risks of exploitation and abuse, unintended pregnancy and HIV and STIs [28,29]. Other factors that impact upon their ability to from relationships are linked to lack of opportunity, social isolation and communication deficits [30,31].

RSE programmes have been developed to address the distinct needs of people with ID. From the available evidence, these programmes appear to include issues such as capacity and consent, anatomy and biology, contraception and sexual behaviours [20]. It is unclear if such RSE programmes have been developed around theoretical behaviour change models with explicit intended outcomes. Ultimately, it is necessary to identify if participating in an RSE programme enhances long-term decision making that impacts positively on relationships. It also remains to be established who is involved in the design and delivery of RSE programmes for people with ID and the extent to which an evaluative process is integral to the approach. Therefore, the aim of this systematic review was to identify the design, content, delivery and evaluation approaches used in RSE programmes for people with intellectual disabilities across the lifespan.

2. Methods

The objectives of the review were:

- to identify who is involved in the design and development of RSE programmes for people with intellectual disabilities,
- to establish the content of the RSE programmes,
- to identify who delivers the RSE programmes and
- to identify if evaluations have been undertaken of the RSE programmes.

Prior to commencing the systematic review, the PROSPERO and Cochrane databases were checked to identify if a similar review had previously been untaken. No such reviews were identified. The preferred reporting items for systematic reviews and meta-analyses (PRISMA) process was followed [32].

2.1. Search Strategy

Ethics Statement

The study is a systematic review of published research evidence therefore ethical approval was not required. An expert subject Librarian assisted with the literature searching. The databases searched were PsycINFO, CINAHL, MEDLINE, and ERIC. The key terms included (i) intellectual disabilities (ii) sexuality (iii) relationships (iv) education and training. To establish if additional relevant studies existed, we hand searched reference lists and also checked Google Scholar to identify any additional papers.

2.2. Inclusion and Exclusion Criteria

Quantitative, qualitative and mixed methods studies were all eligible for inclusion in the review. Studies were included that:

- focused on the design, content, delivery or evaluation of RSE programmes specific to people with ID,
- utilized an empirical research design,
- were published in the English language.
- were published from inception to August 2020.

Studies were excluded that:

- did not focus exclusively on RSE programmes for people with ID,
- did not address the design, content, delivery or evaluation of RSE programmes specific to people with ID,
- were not empirical research,
- were not published in English and
- were grey literature and theses.

Following the search of the databases, studies were screened against the inclusion and exclusion criteria. Two reviewers screened the title and abstracts using the study inclusion criteria following the removal of duplicate papers. The reviewers retrieved and independently screened the full text papers. The reviewers then independently appraised the full text and completed an inclusion and exclusion checklist. Final agreement of the included papers was reached by consensus.

2.3. Data Extraction and Synthesis

Data were extracted on country, study aim, design, sample characteristics, study method, key findings and recommendations. The synthesis of the mixed methods research literature was conducted as part of the systematic review process [33]. The data were thematically analysed to identify the emergent themes across the included studies. Covidence was used to facilitate the review process [34]. Detailed and comprehensive coding and analysis was undertaken with the data verified by the research team. The identified concepts were grouped into themes to enable comparisons and differences to be established across and between the studies and the themes. To address potential bias, the final themes were discussed, verified and agreed by the research team [35].

2.4. Quality Assessment

The appraisal process involved two reviewers. The mixed-methods appraisal tool (MMAT) was used in the assessment of the quality of the included studies [36]. To determine quality, the appraisal questions were systematically applied and a category of 'high', 'medium' or 'low' assigned based on the evidence regarding specific criteria. Of the nine qualitative studies, set out in Table 1, eight scored 'high' [37–44] and one scored 'low' [45].

Table 1. Methodological quality of qualitative studies using MMAT (Hong et al., 2018).

Studies	Q1	Q2	Q3	Q4	Q5	Quality Score
Frawley & Bigby (2014)	Y	Y	Y	Y	Y	H
Lafferty et al. (2012)	Y	Y	Y	Y	Y	H
Löfgren-Mårtenson (2012)	Y	Y	Y	Y	Y	H
Louw (2017)	Y	Y	Y	Y	Y	H
Nelson et al. (2020)	Y	Y	Y	Y	Y	H
Phasha & Runo (2017)	Y	Y	Y	Y	Y	H
Schaafsma et al. (2013)	Y	Y	Y	Y	Y	H
Swango-Wilson (2009)	Y	CT	CT	N	N	L
Wilson & Frawley (2016)	Y	Y	Y	Y	Y	H

Y = yes, indicates a clear statement appears in the paper which directly answers the question; N = no, indicates the question has been directly answered in the negative in the paper; CT = can't tell, indicates there is no clear statement in the paper that answers the question Critical appraisal questions were as follows: 1. Is the qualitative approach appropriate to answer the research question? 2. Are the qualitative data collection methods adequate to address the research question? 3. Are the findings adequately derived from the data? 4. Is the interpretation of results sufficiently substantiated by data? 5. Is there coherence between qualitative data sources, collection, analysis and interpretation?

The three quantitative studies set out in Table 2 achieved 'medium' scores [46–48].

Table 2. Methodological quality of quantitative studies using (MMAT) (Hong et al., 2018).

Studies	Q1	Q2	Q3	Q4	Q5	Quality Score
Katoda et al. (1990)	Y	CT	Y	N	CT	M
Louw (2014)	Y	N	CT	CT	Y	M
Murray (2019)	Y	CT	Y	CT	Y	M

Y = yes, indicates a clear statement appears in the paper which directly answers the question; N = no, indicates the question has been directly answered in the negative in the paper; CT = can't tell, indicates there is no clear statement in the paper that answers the question. Critical appraisal questions were as follows: 1. Is the sampling strategy relevant to address the research question? 2. Is the sample representative of the target population? 3. Are the measurements appropriate? 4. Is the risk of nonresponse bias low? 5. Is the statistical analysis appropriate to answer the research question?

3. Results

The study selection process is set out in Figure 1, with the number of papers identified and included at each stage. Most of the full text articles were excluded as they did not report on the design, content, delivery or evaluation of RSE programmes specific to people with ID.

3.1. Study Characteristics

The 12 papers that met the aim of the review are set out in Table 3. Of the 12 included studies, 9 used qualitative designs and 3 utilised quantitative methods. A range of data collection approaches were used, including questionnaires, individual interviews and focus groups. The largest number of studies were conducted in South Africa (n = 3) and Sweden (n = 3). The others were undertaken in Australia (n = 2), Canada (n = 1), the Netherlands (n = 1), the United Kingdom (n = 1) and the United States (n = 1). The sample sizes ranged from 11 to 600 participants.

3.2. Data Analysis and Synthesis

Following the systematic analysis of the studies, four themes were identified: (i) principles informing RSE programme development; (ii) design and content of RSE programmes; (iii) delivery of RSE programmes; and (iv) evaluation of RSE programmes.

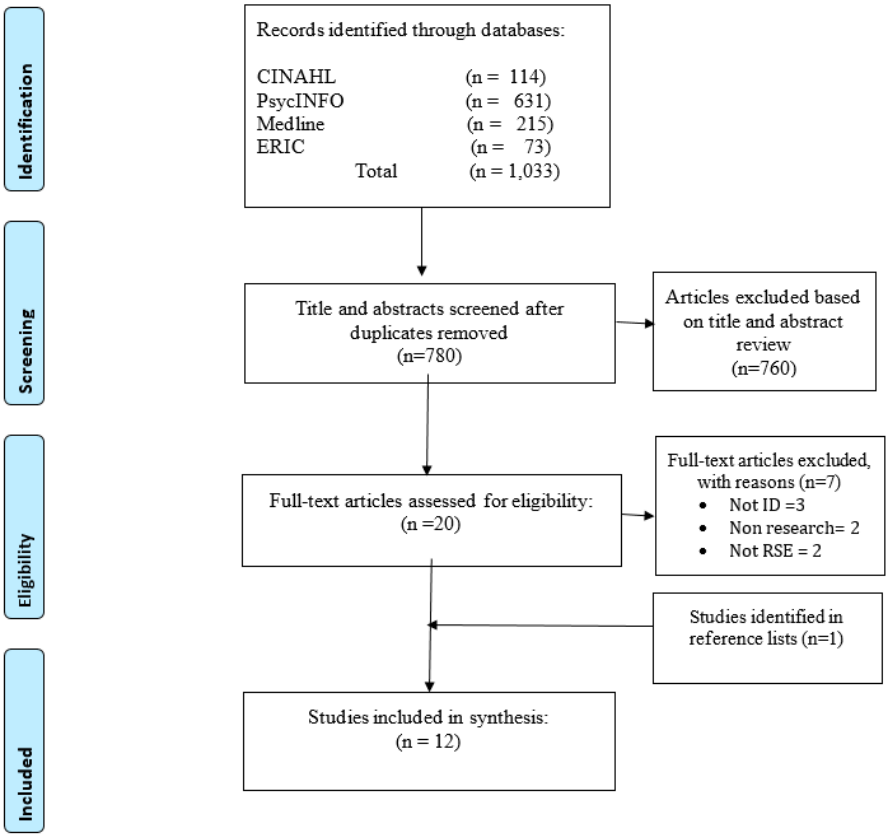

Figure 1. Preferred reporting items for systematic reviews and meta-analyses (PRISMA) flow diagram with search results.

3.2.1. Principles Informing RSE Programme Development

Arising from the current literature review is the need to ensure that RSE programmes for people with ID are informed by underpinning principles and relevant theoretical and behaviour-change models. The principles include parity of access to RSE programmes in keeping with those provided for typically developing children and young people [40,42]. Access to such RSE programmes needs to be viewed as a fundamental right to ensure that people with ID have access to evidence-based structured relationship and sexuality education that is appropriate to their specific needs [37–42]. The current research evidence highlights that existing RSE programmes lack recognised evidence-based models and frameworks. Therefore, the starting point to the development of RSE programmes relevant to people with ID is to ensure that they are built around and informed by relevant theoretical and behaviour change models [39,43]. In a Dutch study investigating five RSE programmes, the use of relevant theories and behaviour change models was found to be absent [43]. Research evidence also indicated that RSE programmes should be established for people with ID across the lifespan, commencing at an early age and continuing on into adulthood, and not delivered as a 'one-off' exercise [42]. The broad focus and intended purpose of some of the RSE programmes were to provide people with ID with the same opportunities as typically developing people. The broad focus being the provision of knowledge and skills to make informed choices and decisions to enable the development of positive sexual identities and benefit from healthy sexual relationships while reducing the possibility of harm [38,42,48].

Table 3. Papers included in the review (n = 12).

Citation and Country	Aim	Design, Content and Delivery	Sample	Methods	Key Findings	Recommendations
Frawley & Bigby (2014) Australia	Identify the experiences of people with intellectual disability (ID) as peer educators in sexuality and relationship education.	Co-produced with people with ID Peer educators	Peer educators (n = 16)	Qualitative: interviews using thematic analysis	People with ID as peer educators acquire new knowledge and skills about relationships and available community resources and supports evident. Sharing their personal insights and experiences as a peer educator resulted in their greater empowerment and confidence.	Participating as a peer educator appears beneficial to individuals. Future work needs to focus on identifying the effectiveness of peer education and the outcomes for programme participants.
Katoda et al. (1990) Sweden	Identify the views of school nurses on health education and sexual relationships for young people with ID.	Health education and interpersonal relationships Delivered within regular curriculum	School nurses (n = 600)	Quantitative: questionnaire using descriptive statistical analysis	Swedish school nurses (47%) were more involved in delivering the programme compared to 1% of Japanese nurses. Nurses identified by parents as most appropriate to deliver sex education followed by teachers. Only 2% of nurse participants thought that nurses should have a lead role due to their limited knowledge of ID issues. 70% of Swedish participants thought nurses required education on ID compared to 91% of Japanese who stated they did not. Swedish nurses provided education on sex and interpersonal relationships, food and exercise and 'our body.'	Sex and relationship education should be fully integrated with the school curriculum and delivered collaboratively by parents, teachers and school nurses. Specific teaching materials need to be developed with guidelines for parents, teachers and school nurses regarding their use.
Lafferty et al. (2012) UK	Identify the barriers to the delivery of relationship and sexuality education (RSE) for people with ID.	Interactive CD-ROM Sex, sexuality and relationships	Family carers, professionals and front-line staff (n = 100)	Qualitative: interviews and focus groups using thematic analysis	Main programme content related to the protection of vulnerable young people with ID and the lack of appropriate training, poor education resources and 'cultural prohibitions.' The barriers need to be identified, discussed and adequately addressed to improve RSE programmes' content and delivery.	Training and information about RSE programmes are required. Risk management procedures need to be in place. RSE programmes should be available to support the empowerment of young people with ID.
Lofgren-Martenson (2012) Sweden	Explore the experiences of sex education programmes in young people with ID.	RSE education framework didactic delivery in gender segregated groups Content more focused on sexual risks	Young people with ID (n = 16)	Qualitative: interviews using thematic analysis	Current programmes focus more on sexual risk opposed to sexual pleasure and intimacy. There is a need for RSE education frameworks and teaching models to assist professionals to deliver RSE education programmes relevant to the needs of young people with ID.	Future studies should include young people with ID. There needs to be collaborators in the research to address different gender perspectives and co-create sex education programmes. Future studies should focus on learning strategies to reduce sexual risk behaviours and promote affirmative attitudes towards the expression of sexuality.

Table 3. *Cont.*

Citation and Country	Aim	Design, Content and Delivery	Sample	Methods	Key Findings	Recommendations
Louw at al. (2014) South Africa	Identify the views of teachers and childcare providers regarding sexuality, HIV and AIDS education in special needs schools.	Health education HIV/AIDS and sexuality education Collaborative approach by teachers and health professionals	Special school educators (n = 78)	Quantitative: questionnaire using descriptive and inferential statistical analysis	Teachers had high level of knowledge regarding the topic area and teaching sexuality education. However, some teachers questioned if they should be responsible for delivering RSE programmes. The personal attitudes and beliefs of teachers has the potential to influence teaching practice.	Policy research required on the impact and outcomes of RSE programmes. A proactive collaborative approach is needed to support RSE programme design and delivery. Tailored RSE materials are required for people with ID. Participatory action research is needed involving all key stakeholders, including young people with ID and their parents to identify the effectiveness of programmes.
Louw (2017) South Africa	Identify the experiences of teachers and school staff when delivering RSE programmes in special needs schools.	Sex education manuals Visual materials re sex and relationships School staff and parental involvement	Teachers (n = 68) School staff (n = 10)	Qualitative: questionnaire using thematic analysis	Students with ID have a fundamental right to receive RSE education relevant to their needs. Appropriate RSE curriculum is required and adequate support available to enable young people with ID to meaningfully engage and participate in RSE programmes.	Need up-to-date, evidence-based RSE programmes that are developed by experts in the field. This may address the possibility of teachers imposing their own values and beliefs. Parents need to be supportive of their children's involvement in structured RSE programmes.
Murray (2019) Canada	Develop, deliver and evaluate a sex education programme for young people with ID.	Community development approach Sexuality, sexual relationships and intimacy Interactive approaches to learning	Young people with mild ID (n = 93)	Quantitative: questionnaire using descriptive statistical analysis	Reinforce the need for sexual health education for young people with ID and increase opportunities to develop healthy sexual relationships and intimacy. RSE programmes need to promote positive sexual identities and decrease risk of sexual harm.	Future research could utilise focus groups to more fully understand the perceptions of young people with ID regarding the education sessions. The benefits of a peer-to-peer model of education delivery needs to be researched.
Nelson et al. (2020) Sweden	Explore the experiences of teaching sexual and reproductive health to students with ID.	Sexual health and reproduction education Various teachers	Teachers (n = 10)	Qualitative: interviews and phenomenological analysis	Teachers are the main source of information for students. Teachers need to adapt content to student needs. Teachers lack knowledge and confidence regarding religion and cultural aspects and lack skills in sexual health issues.	Teachers need access to specific materials and resources. Teacher training programmes must address issues related to culture and different religious ideologies. An evaluation of learning outcomes needs to be undertaken.

Table 3. *Cont.*

Citation and Country	Aim	Design, Content and Delivery	Sample	Methods	Key Findings	Recommendations
Phasha & Runo (2017) South Africa	Identify the sexuality education needs of learners with intellectual disabilities in schools in Kenya.	Erratic and ineffective sexuality education. Mainly risky behaviours School, friends and mothers	Students with mild ID (n = 56)	Qualitative: interviews and focus groups using thematic analysis	Sex education is patchy with no formalised RSE programmes, resulting in a lack in ability to make informed decision regarding sex issues. RSE programmes need to educate regarding avoiding risky or dangerous situations. Content should be well structured to empower young people with ID and include anatomy, health, personal hygiene, reproduction and expressions of love. RSE programmes should begin at an early age.	Teachers require additional training regarding sexuality issues. Future research needs to address topics such as community attitudes towards young people with ID and their sexual and human rights, the benefits of training programmes for teachers, and evaluation of programmes undertaken.
Schaafsma et al. (2013) Netherlands	Explore the development of sex education programmes for people with ID.	Various teaching and learning methods adopted. Knowledge, teaching skills, tailoring, empowerment and enjoying sexuality.	Programme developers (n = 11)	Qualitative: interviews using content analysis	RSE programmes currently lack theoretical models and specific outcomes, and there is a need for systematic evaluations to identify behaviour change. RSE programmes need to include young people with ID in the development.	Future sex education programmes need to be developed using systematic theories, models and evidence-based approaches and be fully evaluated to identify their impact and outcomes. Evidence-based programmes need to be developed involving people with ID at all stages. Professionals need to build upon their experience of working with young people with ID. Further research is required to identify whether sex education programmes decrease the risk of sexual abuse and exploitation. Rigorous RSE programme evaluations are needed to identify effectiveness and outcomes.
Swango-Wilson (2009) USA	Identify the expectations and the development of a sex education programme.	Current materials too broad and overwhelming. Relationship development and skills for responsible sexual activity.	People with ID (n = 3), parents (n = 3), professionals (n = 6)	Qualitative: interviews using thematic analysis	Regarding RSE programme content, parents expressed fear and denial regarding the expression of sexuality. Young people with ID identified relationships and knowledge. ID professionals identified safety and legal issues. Health professionals identified health issues and concerns. Across the groups, all identified the need to involve care givers to enable them to support social, situational learning opportunities.	
Wilson & Frawley (2016) Australia	Identify the support offered to young people with intellectual and developmental disability (IDD).	Transition to work staff (TTW) to include sexuality and relationship information in programmes.	Support staff (n = 17)	Qualitative: focus groups using thematic analysis	Some support workers felt perceived as 'reluctant counsellors'. Participants felt poorly prepared to deliver and discuss sex education and sexuality issues and relied on their own attitudes and values to guide their practice. Possibility of 'blurred' lines between education and social support role.	Further research is needed regarding policy and practice development to inform RSE programme design, delivery and evaluation to identify effectiveness and outcomes.

3.2.2. Design and Content of RSE Programmes

To be effective, RSE programmes require careful design to ensure that content is reflective of the needs and concerns of people with ID. Programmes should be designed around a structured evidence-based education framework and education delivery model and be adapted, where necessary at the point of delivery, to meet the needs of individual students [43,48]. Content should be evidence-based and designed by experts in the field with knowledge and experience of the relationship and sexuality needs and concerns of people with ID across the lifespan [37,45,46]. This is highlighted as important as the providers of some RSE programmes often relied on their own attitudes and values to guide content development [41,44,47]. In an attempt to overcome these issues, several studies identified the need for RSE programmes to be co-designed and co-produced in collaboration with people with ID to ensure they are reflective of their needs and aspirations [37,39,43,46,47]. As part of the co-design and co-production of RSE programmes, families of people with ID also need to be involved to ensure that their issues and perspectives are recognised and included [39,45–47]. This parental involvement is highlighted as important, given their concerns and the often-sensitive nature of pertinent issues, to ensure that the implementation of programmes is both effective and supported [40,46].

Some studies in this review detailed or recommended content for programmes based on the specific views of people with ID and of families and professionals. The suggested programme content varied depending on the concerns and priorities identified by the different groups. A total of five studies specifically referred to programme content from the perspective of people with ID [37,39,42,45,48]. In a study undertaken in the United States (US), young people with ID suggested that programmes should include a focus on intimate relationships and the acquisition of knowledge regarding sexuality and sexual expression [45]. In a Swedish study, young people with ID suggested content that included promoting a more affirmative and empowering approach towards the expression of sexuality and intimacy. Participants wanted more knowledge about sexually transmitted infections (STIs) and pregnancy concerns [39]. An Australian study described four educational sessions focusing on sex and relationships, rights and being safe and respectful relationships [37]. In one study undertaken in Kenyan schools, study participants highlighted that programme content needs to move beyond risk and harm and also include a focus on supporting human rights and addressing issues related to stigma and negative stereotyping of people with ID [42]. From a practical perspective, the participants recommended that programmes include health, personal hygiene, reproductive health and options regarding the expressions of intimacy [42]. A Canadian study involving young people with ID suggested that programmes include a focus on sexuality, sexual relationships and intimacy, as a means to promote choice and enhance positive sexual identities, another important facet related to recognising and discriminating between appropriate and inappropriate sexual behaviours and where to seek help [48].

From the perspective of parents of young people with ID, they expressed concerns about addressing the risk of sexual abuse and potential harm within programmes [45]. Contrastingly, the issues identified by teachers, health personnel and ID professionals include sex and interpersonal relationships, nutrition and physical activity, anatomy and physiology and reproductive health [45,46]. However, differing perspectives existed for some professionals regarding the inclusion of information on sexual harm prevention, health concerns and legal issues [45,48]. Other issues identified as necessary by health professionals included STIs, contraception and pregnancy issues and sex and interpersonal relationships [45,46]. For some teachers, RSE programme content should include bodily self-care; sexuality expression in sexual relationships; STIs, HIV and AIDS; contraception and pregnancy and online social behaviour [41,42,47].

3.2.3. Delivery of RSE Programmes

From this review of the literature, no professional group emerged as the 'natural' one to deliver RSE programmes. People with ID have been identified as peer educators in the co-delivery of RSE programmes, however, further research is required on the effectiveness of this approach and the outcomes achieved [37,39,48]. To be effective, it is suggested that RSE programmes need to be fully integrated within the school curriculum for young people with ID [40,46]. Furthermore, one study

suggested that RSE programmes should be delivered collaboratively between teachers, nurses and parents [46]. A proactive and positive approach was identified as important regarding programme delivery, involving key stakeholders, including young people with ID, parents and teachers [42,45,46,48]. Additional support was also identified as necessary to ensure that all young people with ID can fully engage in RSE progammes, supported by delivery guidelines to ensure consistency and access to tailored resources [38–40,42]. Two groups were identified who currently deliver programmes: nurses and school teachers. However, there are mixed views regarding the knowledge and skills required to confidently and effectively deliver RSE programmes [39,41,46]. Some teachers in one study were of the view that they had the relevant knowledge and skills but questioned if they were best placed to deliver RSE programmes [47]. In another study, teachers were of the view that there were gaps in their knowledge, notably around sexual health and cultural and religious aspects [41]. In another study, social care support workers questioned their role regarding sex education highlighting the possibility of role confusion [44]. Further education and practice development opportunities were identified as necessary to enable professionals to develop the necessary knowledge, skills and confidence in RSE programme delivery [42,46].

3.2.4. Evaluation of RSE Programmes

To evidence their effectiveness, RSE programmes need to incorporate clear outcome measures and include formal evaluation, an integral element of delivery to identify impact and whether the intended outcomes have been achieved [41–43]. It is highlighted that programme evaluation and research should involve all key stakeholders including young people with ID and their parents [47]. Further, long-term follow-up is required to identify sustained behaviour change overtime [43]. Effective RSE programme evaluation is required to identify the impact by decreasing sexual abuse and exploitation [48]. While recommended in two studies, RSE programmes involving peer educators with ID need to be systematically and rigorously evaluated to identify their effectiveness and outcomes achieved [37,48]. One study suggested that the evaluation of RSE programmes also needs to identify the changing attitudes of communities towards people with ID and their right to equality to have relationships and express their sexuality [42].

4. Discussion

The twelve studies included in this systematic review were predominantly undertaken within the past ten years. One study was undertaken in Sweden and Japan in 1990 [46]. The research attention over the past decade may be due to several factors. The first may relate to the attention being given to the need for RSE programmes for all children and young people to ensure that they are equipped with the knowledge and skills to enjoy satisfying and fulfilling adult lives [49]. Another driver for the research focusing on people with ID may be due to concerns regarding the risks, such as exploitation and abuse, and wider sexual health concerns [28]. Three of the papers included in the current systematic review were conducted in Africa in response to concerns regarding sexuality and, more specifically, HIV and AIDS [40,42,47]. Evidence suggests that there are over five million people living with HIV in South Africa with the needs of people with disabilities, including those with ID, largely ignored. As a consequence, this may have influenced the need to conduct the three studies within Africa. Sweden, in contrast, has had a long history of providing mandatory sexuality education since 1955, which has evolved and is fully integrated in the school curriculum. Three of the studies were conducted in Sweden and are set within the wider context of the right to access sexuality education for all [39,41,46]. Therefore, the focus on RSE programmes from the perspective of people with ID may be driven by this rights and social inclusion agenda.

An important finding from the current systematic review relates to the evolving RSE programme research that identifies the design, delivery and outcomes achieved and their impact on behaviours over time. It is also evident that there is an absence of evidence-based RSE programmes that address the specific needs and concerns of people with ID across the lifespan, notably after the transition

into adulthood. What is also required to be established is the evidence and processes utilised in the development of RSE programmes and who has the relevant knowledge, skills and confidence to effectively deliver such programmes. It is also yet to be established what the long-term benefits and outcomes are as a result of the existing programmes. This therefore indicates the pressing need for a policy focus, practice development and education initiatives to advance this agenda.

4.1. Policy

With the growing need to ensure that RSE programmes are available and accessible to all children, including those with disabilities or special needs, the UK Government have embedded RSE programmes into the school curriculum for all pupils in primary and secondary schools from autumn 2020 [17,50]. While the RSE needs of young people with ID are distinct and responses will inevitably change over time, the guiding policy is that they have the same fundamental right to access education programmes as typically developing children and young people, one of which is access to evidence-based RSE programmes [40,51]. It is evident from the findings arising from the current systematic review, that access to age-appropriate and evidence-based RSE programmes within the education system is required for young people with ID and that need continues into adulthood. An important finding from the current systematic review is that the focus of existing RSE programmes is on children and young people with ID. Only one study focused specifically on the RSE needs of adults with ID [37]. Therefore, future policy initiatives need to ensure that the needs of all people with ID are included, not only children and young people. Such programmes are required to prepare people with ID across the lifespan to form and maintain healthy relationships such as friendships, and sexual relationships including intimacy [17].

To date, and as evidenced in the current review, RSE programmes vary in content, with no 'natural' professional or parent emerging as best placed to deliver them. Rather, it is apparent that RSE programme design and delivery needs to be a collaborative approach in which young people and adults with ID, their parents and professionals all play crucial roles. The content of RSE programmes can be a contentious issue for some parents and professionals. However, it is important to note that concerns including consent, same-sex relationships and online presence such as sexting, pornography and cyberbullying feature in the recommended UK RSE programme content [17,50]. There is broadening of the traditional views and perceptions of what may constitute RSE programme content; it must be specific to the needs and concerns of children, young people and adults with ID. While it is possible to embed RSE programmes as a compulsory subject in the school curriculum, this is not the case for adults with ID and is an area that needs to be addressed. For children and young people with ID, parents remain the primary educator and therefore they need to be fully involved in the process [17]. It is also necessary to identify additional resources to support and enable conversations at home regarding relationships and sexuality issues thereby promoting the confidence of parents [50]. To be effective, young people with ID, parents and professionals must work collaboratively to maximise RSE programme content, delivery and evaluation.

4.2. Practice

From a practice perspective, this review highlights the need for professionals to develop the necessary skills and knowledge to deliver RSE programmes with confidence to young people with ID [42]. The prerequisite knowledge and skills are required to ensure that programme delivery responds to the specific needs of young people and adults with ID [43,44]. This is necessary to be responsive to different learning styles and needs. Young people and adults with ID need to be involved in all stages of the development of RSE programmes as the ultimate recipients [44,45]. The UK Government statutory guidance also highlights the need for professionals to work collaboratively with parents to facilitate communication, thereby helping to ensure that RSE programmes respond to and continue to meet the needs of the young person with ID and recognise their concerns [17].

The current review highlights the importance of formally evaluating the outcomes achieved following RSE programme delivery [48]. Evaluations need to be undertaken through the lens of people with ID

to ensure RSE programmes reflect, respond and adapt to their specific concerns and priorities. These personal perspectives, either individually or as part of a wider group, can be used to inform the review and modification of RSE programmes, thereby ensuring they are contemporary [48]. Additionally, RSE programme reviews need to include the views of parents and professionals, thereby helping to ensure they remain contemporary and responsive to their concerns for their family member with ID, such as maintaining and sustaining positive and healthy relationships and minimising the potential for sexual abuse or unintended pregnancies [41]. To be effective, RSE training programmes must also enable professionals involved in their delivery to address cultural and religious beliefs that exist within different communities in a way that is relevant and acceptable [42].

4.3. Education

RSE programmes for young people with ID should be fully integrated within the school curriculum, be built upon education frameworks and effective teaching models and use evidence-based interventions to aid professionals in their delivery [52]. School teachers are one of the main sources of information for students, therefore, educating them in RSE programme delivery is necessary to promote the principles of inclusive education [44]. Education and training as part of general teacher preparation and continuing professional development (CPD) programmes should be developed and provided to improve the knowledge, skills and confidence of teachers to facilitate the effective delivery of RSE programmes [53]. It is important that teachers receive the appropriate training to be able to address issues related to culture and different religious beliefs [54]. This is necessary to support the adaptation of the content of RSE programme learning resources and materials to enable meaningful engagement and participation [20].

Health professionals require psychoeducation to develop their understanding of the importance of RSE for children, young people and adults with ID and recognise how the provision of RSE can help in reducing and preventing health and psychological problems across the lifespan [55]. In addition, as part of their general training or CPD all health care professionals require education about intellectual disabilities and their specific health needs [56]. Moreover, parents and families also have education and support needs that may enhance their understanding, attitudes and response regarding the changing needs of children with ID as they mature and develop into adulthood [57]. Some people with ID may experience challenges in forming and expressing their sexual identity [29]. Significant barriers to this include societal perceptions of people with ID and the impact of multiple disadvantages with regard to gender, sexuality and disability [58]. The removal of barriers through the provision of training and education can play a vital role in supporting young people and adults with ID to express their sexual identity and develop fulfilling relationships [24]. Efforts to educate the wider public about the relationships and sexuality rights of people with ID is also necessary to promote equality and inclusion [59,60].

5. Strengths and Limitations

A strength of the current systematic review is the identification of important issues regarding the design and development of RSE programmes relevant to the needs of children, young people and adults with ID. Attempts have been made to address the relationship and sexuality concerns of young people with ID, however, there has been a limited focus on extending these education initiatives and developments as they move into adulthood. Any RSE programme needs to be underpinned by relevant theoretical models to enable and sustain behaviour change. There is a need to evaluate outcomes and their long-term impact in influencing the relationship and sexuality experiences of people with ID across the lifespan. There is a lack of transcultural perspectives that needs to be recognised and responded to in RSE programme development. There were no multi-centre international research studies identified. The researchers sought to be rigorous in approach while conducting the review and acknowledge the potential for bias.

6. Future Research

Existing RSE programmes for both young people and adults with ID lack a theoretical basis [43]. Therefore, future RSE programmes need to be developed using systematic theories, models and evidence-based approaches and be fully evaluated to identify their impact and outcomes [42]. The use of multi-centred studies will determine the effectiveness of theoretically driven, structured RSE programmes that are specific to the distinct needs of young people and adults with ID and their families and professionals with a national, international and transcultural focus. Future RSE programme development needs to include children, young people and adults with ID in all aspects of their development. The concept of co-production should be at the core of all RSE programme design and development to ensure the needs and concerns of people with ID are integrated and accurately reflected [61,62]. A future research focus needs to identify the outcomes of RSE programmes that enable young people and adults with ID to develop positive sexual identities and decrease risk of sexual harm, unintended pregnancy and sexually transmitted infections [29]. There is also scope to undertake research studies that focus on the effects of religious and cultural beliefs and attitudes and the impact of RSE programmes for people with ID [63]. Prioritising research in these areas will help to address inequalities and enable young people and adults to make informed decisions about forming relationships and the expression of their sexuality.

7. Conclusions

It has become increasingly apparent through this systematic review of the research evidence that people with ID have distinct needs regarding their relationship and sexuality concerns. There is an evolving research evidence base regarding the design and delivery of RSE programmes to address their specific issues. While these developments are positive, it is important to recognise the limitations that exist regarding the RSE programmes currently available. It is apparent that any future RSE programmes must be designed around a recognised and evidence-based theoretical model that is effective in enabling and sustaining behaviour change. RSE programme content may be an area of contention and potential conflict, due to the potentially differing views of people with learning disabilities and their families. It is recommended that to be acceptable, people with learning disabilities, their families and professionals must all work collaboratively on the programme content design, which should also be informed by the research evidence base. It is necessary that all stakeholders are fully involved to ensure that the range of issues and concerns are fully reflected within the RSE programme. Failure to consider these important issues may result in poor uptake. The two key professional groups that emerged as those most commonly involved in the delivery of RSE programmes are school teachers and registered nurses. Some were of the view that they did not possess the necessary knowledge and skills to confidently deliver RSE programmes to people with ID. Therefore, to address these needs it is necessary to provide access to education and practice development initiatives that build their knowledge, skills and confidence. While it is apparent that there are RSE programmes being provided to some people with ID, it is yet to be established what their impact is in effecting long-term behaviour change. Arising from this, there is a pressing need to integrate clear outcome measures within all RSE programmes to enable the outcomes achieved to be identified. Additionally, there are no longitudinal studies in existence that identify the outcomes achieved regarding the development of positive and healthy relationships, intimacy and the expression of sexuality by people with ID. These are aims of RSE programmes and are therefore areas requiring further research attention.

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People with intellectual disabilities, relationship and sex education programmes: A systematic review

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Abstract

Objective: The aim of this systematic review was to examine the research evidence concerning the views and experiences of people with intellectual disabilities regarding their participation in and the effectiveness of relationship and sex education programmes.

Methods: A systematic search of relevant electronic databases was conducted using defined inclusion criteria. All papers reviewed were from October 1998 to October 2018. PRISMA guidelines were followed in the design and reporting of the systematic review.

Results: A total of eight studies published in English were included in the review. Data were analysed and the key themes identified were (1) designing and developing relationship and sex education programmes, (2) participating in relationship and sex education programmes and (3) perceived benefits of relationship and sex education programme participation.

Conclusion: This review identified that people with intellectual disabilities are accessing relationship and sex education programmes and appear to find them helpful. Further research is required to investigate the extent to which programmes impact on long-term behaviours that enable the development of sustainable relationships and reduce the unintended consequences of sexual activities. Implications for policy, practice and future research developments are discussed.

Keywords

Intellectual disabilities, programmes, sex education, sexuality education, systematic review

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Introduction

Sexuality is a fundamental part of being human and takes multiple and diverse forms. The World Health Organization (2015) has conceptualised sexuality as

> .... the possibility of having pleasurable and safe sexual experiences, free of coercion, discrimination and violence. Indeed, it has become clear that human sexuality includes many different forms of behaviour and expression, and that the recognition of the diversity of sexual behaviour and expression contributes to people's overall sense of well-being and health. (p. 4)

Arising from this position, there is a global interest in ensuring equality of access to appropriate healthcare and health education for all (Australian Human Rights Commission, 2014; Department of Health, 2013; Ontario Human Rights Commission, 2014), and for specific groups with distinct needs such as young people, people with mental health issues and people with intellectual disabilities (IDs; McCann et al., 2019; Sun et al., 2018; Whittle and Butler, 2018). In terms of evidence-based research, there is a growing body of literature regarding the general youth population investigating sexual health improvement and prevention concerns such as HIV, sexually transmitted infections (STIs), pregnancy and early childbearing (Bailey et al., 2010; Henderson et al., 2007; Oringanje et al., 2009; Shepherd et al., 2010). Influenced by the wider research evidence and social concerns, there is an increased attention and recognition of the need for structured evidence-based relationship and sexuality education (RSE) programmes. It is routine practice for RSE programmes to be delivered directly to young people in school settings as an integral part of the mainstream education curriculum (Lohan et al., 2018). In this regard, the factors that make RSE programmes effective, acceptable, sustainable and implementable have been explored (Pound et al., 2017). A key aim of RSE programmes is

> To embrace the challenges of creating a happy and successful adult life, pupils need knowledge that will enable them to make informed decisions about their wellbeing, health and relationships and to build their self-efficacy. Pupils can also put this knowledge into practice as they develop capacity to make sound decisions when facing risks, challenges and complex contexts. Everyone faces difficult situations in their lives. These subjects can support young people to develop resilience, to know how and when to ask for help, and to know where to access support. (Department of Education, 2018, p. 6)

In some countries, governments have established policies to support the RSE needs of young people with a clear focus on the implementation of RSE programmes within mainstream schools (Department of Education, 2018). More recently, Scotland has gone further to become the first country in the world to embed the teaching of lesbian, gay, bisexual, transgender and intersex (LGBTI) rights within the school curriculum (Scottish Government, 2018). Similarly, there have been significant developments and improvements in the lives of people with ID in recent decades. These changes have seen a move away from institutional models of education and care to more inclusive supports within the community. Part of these intentions have been to enable people with ID to have more autonomy and control over their lives and the decisions they make (Department of Health, 2009; Scottish Government, 2013). These decisions must also include those related to the expression of their sexuality and all that this entails.

The existing literature recognises the rights of people with ID to have fulfilling lives and make independent life choices (Curryer et al., 2015; Family Planning Association, 2006). People with ID want friendships, meaningful relationships and some may want sexual intimacy (Brown and McCann, 2018). However, the expression of sexuality is an area where potential freedoms are often limited, compared to the non-ID population (Jahoda and Pownall, 2014). In addition, people with

ID are often misperceived as being either asexual, hypersexual or sexually immature (Conder et al., 2015). Studies have highlighted the potential conflicts that exist between autonomy versus vulnerability, exploitation and risk of harm, acknowledging that supportive interventions can help to address some of the concerns (Fisher et al., 2016). Parents and families of people with ID and education, health and social care practitioners recognise that many people with ID are interested in and engage in sex. However, people with ID often possess less knowledge about sexuality, display more inappropriate sexual behaviours and may not understand the consequences of engaging in unprotected sex (Ballan, 2012).

Young people with ID are more likely to practise unsafe sex and are at an increased risk of sexual abuse and exploitation (McDaniels and Fleming, 2016). They are less likely to use contraception, have an increased risk of unintended pregnancy, and a greater exposure to HIV and STIs, compared to the non-ID population (Jahoda and Pownall, 2014). They may also have difficulties in forming and maintaining healthy relationships due to limited communication skills, loneliness, social isolation and low self-esteem (Baines et al., 2018). There is well-established evidence that indicates that people with ID are further at risk of developing mental health conditions such as anxiety, depression and post-traumatic stress disorder (PTSD; Public Health England, 2016). While some RSE programmes have been developed for people with ID to address these concerns, they appear to focus on knowledge acquisition regarding the biology of sex, risky sexual behaviours and capacity and consent, lacking a wider focus on relationships, intimacy, informed choice and decision making (Baines et al., 2018). Furthermore, it is well recognised that people with ID experience barriers to accessing health care, health prevention programmes and health education that it relevant and appropriate to their particular needs (Truesdale and Brown, 2017). While there is evidence of RSE programme delivery specific to the needs of people with ID and their families and carers, it remains to be established if the programmes are accessible, acceptable and outcome-focused. Therefore, the purpose of this review was to identify the views and experiences of people with ID regarding their participation in RSE programmes and how they perceive their effectiveness. It will also highlight issues that address future policy, practice and research and provide recommendations for future RSE programme developments.

Methods

Review questions

1. What are the views and experiences of people with ID regarding their participation in RSE programmes?
2. What is the perceived benefits of RSE programmes from the perspective of people with ID?

Search strategy

A subject Librarian assisted with the literature searching. The databases searched were PsycINFO, CINAHL, MEDLINE and Sociological Abstracts. An example of the search strategy used in one electronic database is shown in Table 1.

The data sources drawn upon were published from October 1998 to October 2018 and were limited to academic peer reviewed research papers written in English. This review considered studies that utilised qualitative, quantitative and mixed-methods approaches. The PRISMA guidelines were followed in the design and reporting of the systematic review and a flow chart is provided (Figure 1) that contains the results of the searches (Moher et al., 2015).

Table 1. CINAHL search strategy and results.

Search code	Query	Results
S1	intellectual disab*	20,552
S2	mental retard*	2,877
S3	mental handicap	468
S4	developmental disab*	9,798
S5	learning disab*	7,691
S6	intervention	331,863
S7	education	556,834
S8	training	164,554
S9	programme*	403,294
S10	sexual behaviour	10,089
S11	sexual*	85,009
S12	intimacy	2,942
S13	relationship* or love	278,135
S14	friendship*	5,825
S15	S1 OR S2 OR S3 OR S4 OR S5	34,182
S16	S6 OR S7 OR S8 OR S9	1,138,085
S17	S10 OR S11 OR S12 OR S13 OR S14	355,044
S18	S15 AND S16 AND S17	1,205
S19	Limiters: Years 1998–2018; academic journals; English language	510

Inclusion criteria

Included studies had to explicitly address the views and experiences of people with ID and their participation in RSE programmes. The settings included schools and health and social care services. Studies that did not focus specifically on the views and experiences of people with ID were excluded.

Study selection and data extraction

Following the removal of duplicate papers, two reviewers (E.M. and L.M.) screened the titles and abstracts based on the inclusion criteria. Full-text papers were retrieved and screened independently by the same reviewers. Any disagreements were resolved by critical discussion.

Quality assessment

Two reviewers (E.M. and L.M.) appraised the included papers for methodological quality. An internationally recognised and widely used critical appraisal tool was selected from a range of possible options to assess the quality of the selected papers (Critical Appraisal Skills Programme, 2018). A total of 10 questions were applied to the data (Table 2). Each item was rated as 'yes', 'no', and 'can't tell'. A 'yes' response indicated that a clear statement appeared in the paper that directly answered the question. 'No', indicated that the question was answered negatively in the paper, and 'Can't tell', indicated that there was no clear statement relating to the question. There was a high number of 'yes' responses across most of the papers for a significant number of questions indicating good quality overall. Question number 6 had particularly low ratings involving the consideration of research relationships. Any disagreements

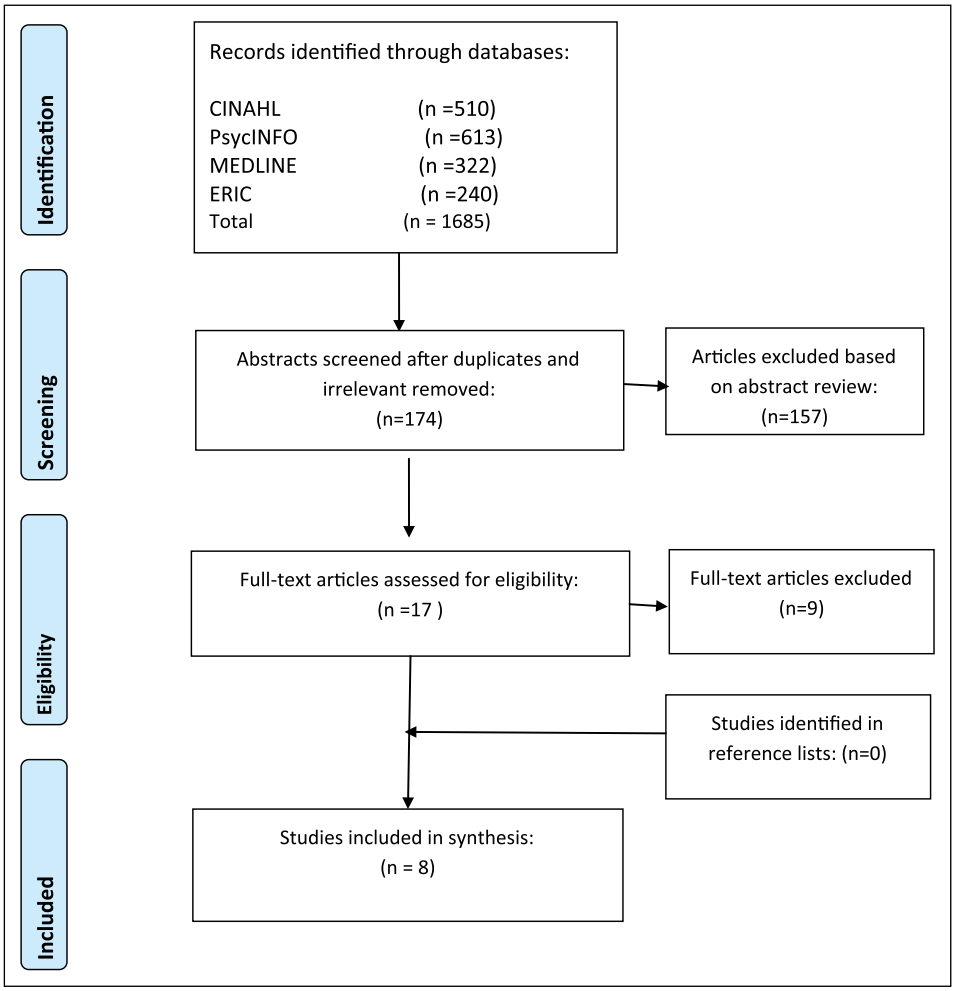

Figure 1. PRISMA flow diagram with search results.

were discussed with a third reviewer (M.B.) and consensus reached. All of the studies addressed the objectives of the review and were therefore deemed suitable for inclusion.

Characteristics of the studies

The data were extracted by two of the reviewers (E.M. and M.B.) and verified by a third reviewer (L.M.). The eight papers that addressed the systematic review aims are presented in Table 3. Most studies ($n=3$) were conducted in Australia. The remainder were carried out in Ireland ($n=2$), Sweden ($n=1$), the UK ($n=1$) and the USA ($n=1$). Sample sizes ranged from 4 to 5,070 study participants involving young people and adults with ID. A selection of data collection methods was used in the studies including survey, questionnaires and interviews. A total of three studies were quantitative, adopting a range of measures and survey approaches, four studies used qualitative approaches including interviews or focus groups, and one paper used a mixed-methods design.

Table 2. CASP quality scores.

CASP criteria	Barnard-Brak et al. (2014)	Dukes and McGuire (2009)	Finlay et al. (2015)	Frawley and Bigby (2014)	Frawley and Wilson (2016)	Gardiner and Braddon (2009)	Garwood and McCabe (2000)	Löfgren-Mårtenson (2012)
1. Clear statement of aims	Y	Y	Y	Y	Y	CT	Y	Y
2. Appropriate methodology	Y	Y	Y	Y	Y	Y	Y	Y
3. Appropriate research design	Y	Y	Y	Y	Y	N	Y	Y
4. Appropriate recruitment strategy	Y	CT	Y	N	Y	Y	Y	Y
5. Appropriate data collection methods	Y	Y	Y	Y	Y	CT	Y	Y
6. Research relationships Considered	N	N	CT	CT	N	N	N	CT
7. Consider ethical issues	N	Y	Y	Y	Y	N	Y	Y
8. Rigorous analysis	Y	Y	Y	Y	Y	CT	CT	Y
9. Clear findings	Y	Y	Y	Y	Y	CT	CT	Y
10. Value of the research	Y	Y	Y	Y	Y	Y	CT	Y

CASP: Critical Appraisal Skills Programme Y: Yes; N: No; CT: Can't tell.

Data synthesis and analysis

In conducting the systematic review, suitable methods for synthesising mixed literature sources were applied (Mays et al., 2005). A detailed and comprehensive thematic analysis of the data was undertaken. All of the emergent themes were systematically identified across the studies and coded by E.M. and M.B., with further verification provided by LM. The themes were grouped into concepts to allow for contrasts and comparisons to be made between themes and studies. The research team (E.M., L.M., M.B.) discussed, verified and agreed on the final themes (Caldwell et al., 2011).

Results

Following the systematic analysis of the studies, three key themes were identified: (1) designing and developing RSE programmes, (2) participating in RSE programmes and (3) perceived benefits of RSE programme participation.

Designing and developing RSE programmes

Any planned RSE programme developments need to ensure that young people and adults with ID are fully involved in programme content to reflect their particular learning requirements (Dukes

Table 3. Papers included in the review ($n = 8$).

Study citation, country & setting	Aims	Sample	Study setting	Data collection method	Key findings	Recommendations
Barnard-Brak et al. (2014) USA	Identify factors influencing the delivery of sex education to students with ID	5,070 students with an ID Aged 14–18 years Teachers	Schools	National longitudinal survey	Findings suggest that many students do not receive sex education and some teachers believe that RSE would benefit these students. The more severe the ID the less likely students are to receive sex education when compared to non-ID students. The more developed the level of expressive communication skills influences participation in RSE programmes.	There should be equal access to RSE programmes for all people with ID. RSE programme development and delivery should include collaboration between people with ID, health educators, special education teachers.
Dukes and McGuire (2009) Ireland	Evaluate a sex education intervention to improve knowledge and capacity in people with a moderate ID	People with ID Male ($n = 2$) Female ($n = 2$) Aged 22–23 years	Social care	Questionnaires	All study participants improved their decision- making, capacity to consent on all measures: consent, sexual knowledge and safety practices.	Larger efficacy study using mixed methods and RSE programmes delivered to groups based on shared learning needs required. Development of a sex education website and evaluate its effectiveness. Include LGBT issues in future RSE programme content.
Finlay et al. (2015) UK	Examine 'understanding' and identify barriers in delivering a sex education programme for people with ID	Young people with ID Aged 16–19 years Teachers ($n = 16$)	Schools	Interviews and video content analysis	Effective communication important as long sentences and abstract concepts can impact on understanding. Analysis of the videos identified contextual issues that can impact upon understanding.	Further research needed to examine further how RSE programmes are delivered more effectively and potential solutions identified.

(continued)

Table 3. (Continued)

Study citation, country & setting	Aims	Sample	Study setting	Data collection method	Key findings	Recommendations
Frawley and Bigby (2014) Australia	Explore the experiences of a co-facilitated relationships and sex education programme involving people with ID	Peer educators with ID ($n=16$) Ages 20–40 years	Social care	Interviews	Peer educators with ID felt empowered as credible trainers with skills to support others with ID.	Further research is required to identify the impact of people with ID as peer educators in RSE programme delivery.
Frawley and Wilson (2016) Australia	Explore the views and experiences of participating in a sexuality education programme	Young men ($n=14$) Young women ($n=11$) Aged 17–20 years	Schools and social care	Focus group interviews	Participants had some knowledge about relationships and sex issues but had limited access to information. Wanted the opportunity to explore sexual interests, desires and experience sexual relationships to develop their knowledge.	Sexuality and relationship education and information needs to be accessible to young people with intellectual disability, with peer support. Want to be fully involved in the design and delivery of RSE programmes.
Gardiner and Braddon (2009) Ireland	Evaluate a sex and relationship education programme for people with ID	People with ID ($n=60$). Ages undefined	Social care	Interviews	Participants reported improvements in self-esteem and knowledge of sexuality issues and knew more about rights and responsibilities.	More RSE programmes required to raise awareness of issues and advocate for and support people with LD in the full expression of their sexuality.
Garwood and McCabe (2000) Australia	Evaluate the knowledge and experiences of men with ID participating in two RSE programmes.	Men with ID ($n=6$) Aged 12–25 years	Social care	Questionnaires	Identified improvements in knowledge. All participants had difficulty taking about their sexuality. Following participation, positive feelings identified about previous sexual experiences.	Knowledge and feelings should be assessed in all RSE programmes and fully evaluated. Utilise recognised theoretical models in RSE programmes. Further research required using larger samples.

Table 3. (Continued)

Study citation, country & setting	Aims	Sample	Study setting	Data collection method	Key findings	Recommendations
Löfgren-Mårtenson (2012) Sweden	Explore RSE for young people with ID	Young people with ID Females ($n = 9$) Males ($n = 7$) Ages 16–21 years	Schools	Interviews	RSE programme content focused on risky sexual behaviours over pleasure, desire and intimacy.	RSE programmes need to include content focusing on pleasure, desire and intimacy. A critical education approach within RSE programmes is needed to challenge gender and sexuality norms and assumptions. Future studies should include youth with ID as both participants and collaborators in research.

ID: intellectual disability; LD: learning disability; RSE: relationship and sexuality education; LGBT: lesbian, gay, bisexual, transgender and intersex.

and McGuire, 2009). The concept of co-production should be at the core of all RSE programme design and developments to ensure the needs and concerns of people with ID are integrated and accurately reflected (Frawley and Bigby, 2014). This is viewed as important as concerns have been expressed that people with ID have not been fully involved in the development of the existing RSE programmes. This was regarded as a limitation, given the emphasis on the assurance that RSE programmes are 'fully responsive to their needs and concerns' (Frawley and Wilson, 2016; Gardiner and Braddon, 2009). Furthermore, peer educators, where people with ID educate and support other people with ID, was suggested as a possible useful educational approach. The findings from one study suggested that peer educators may be beneficial in facilitating the acquisition of new knowledge about forming and maintaining relationships, developing relationship skills and facilitating access to networks and community resources. It was also suggested that the role of peer educator benefitted the individual by developing their own knowledge and increasing their confidence and self-esteem (Frawley and Bigby, 2014). For the effective development of RSE programme content, it was highlighted that a collaboration involving young people with ID, health professionals and special education teachers was seen as necessary (Barnard-Brak et al., 2014). Therefore, RSE programme content development needs to be based on the identification and inclusion of shared learning needs, including lesbian, gay, bisexual and transgender (LGBT) issues and concerns (Dukes and McGuire, 2009; Löfgren-Mårtenson, 2012). There is also a need to ensure that RSE programmes enable participants to recognise and critically question the prevailing sexuality and gender norms and assumptions that exist. Furthermore, there is a tendency for current RSE programme content to focus on concerns regarding 'risky sexual behaviours' to the exclusion of other aspects such as pleasure, desire and intimacy (Löfgren-Mårtenson, 2012).

Participating in RSE programmes

Several of the study findings suggest that RSE programmes were valuable to the participating young people and adults with ID (Dukes and McGuire, 2009; Finlay et al., 2015; Frawley and Wilson, 2016; Gardiner and Braddon, 2009; Garwood and McCabe, 2000; Löfgren-Mårtenson, 2012). One study indicated that the increasing severity of ID may influence whether individuals were included or participated in RSE programmes (Barnard-Brak et al., 2014). However, concerns regarding the implementation and delivery of RSE programmes were related to a lack of prior knowledge and understanding of relationship and sex issues as well as limitations related to effective communication (Finlay et al., 2015; Frawley and Wilson, 2016; Gardiner and Braddon, 2009; Löfgren-Mårtenson, 2012).

For some participants, undertaking RSE programmes was made more challenging by the use of long sentences and abstract concepts. This effected their comprehension and understanding of the programme content, resulting in confusion that detracted from the individual's understanding of already complex and sensitive topics (Finlay et al., 2015).

It was evident that expressing sexuality and talking about it was considerably difficult for some study participants and this situation further compounded their limited understanding of relationship and sexual knowledge (Finlay et al., 2015; Frawley and Wilson, 2016; Garwood and McCabe, 2000). As a consequence of participants' limited knowledge and access to information regarding relationships and sex, there was a natural curiosity to know more about the issues (Frawley and Wilson, 2016).

Another concern identified as impacting RSE programme delivery was the lack of a clear theoretical framework with an absence of measurable outcomes and improvement in knowledge and application (Garwood and McCabe, 2000). It was noted in one study that there was a particular focus on 'risky sexual behaviours' rather than the potential for positive and meaningful relationships (Löfgren-Mårtenson, 2012).

Perceived benefits of RSE programme participation

A recurring theme for young people and adults with ID related to the positive benefits and willingness to take part in the RSE programmes (Dukes and McGuire, 2009; Gardiner and Braddon, 2009; Garwood and McCabe, 2000). People with ID enjoyed the opportunity to meet with others to share and learn from each other. Wider benefits to participation from the perspective of people with ID were improvements in self-esteem, positive feelings about sexual experiences and improved knowledge of sexuality issues (Gardiner and Braddon, 2009; Garwood and McCabe, 2000). Additional benefits were also identified with further positive outcomes identified for some by way of improved decision-making capacity. The improvements in decision-making related to consent to sexual relations and the right to decline. Participants also reported improvements in sexual knowledge and the importance of personal safety practices (Dukes and McGuire, 2009).

Discussion

The aim of this systematic review was to ascertain the views and experiences and perceived benefits of participating in RSE programmes. The findings highlight wider areas requiring attention and development to more fully meet the relationship and sexuality needs of people with ID. Implications for policy, practice and future research developments are discussed. From the systematic review and critical appraisal of the literature, it is apparent that there are difficult and complex issues that need to be addressed, with many people with ID continuing to lack essential knowledge and understanding to make informed decisions regarding meeting their relationship and sexuality needs (Frawley and Wilson, 2016; Gardiner and Braddon, 2009).

A diverse range of attitudes and values already exist regarding relationships and the expression of sexuality by people with ID, their families and practitioners and within wider society (Brown and McCann, 2019; Hall, 2010). These include paternalistic behaviours, heteronormativity, prejudice and discrimination. Compounding this position is the prevailing views that people with ID are either asexual or hypersexual (Yau et al., 2009). Therefore, RSE programmes need to focus on challenging established gender, relationship and sexuality norms and assumptions (Löfgren-Mårtenson, 2012). The reality, from the perspective of people with ID, is that most simply seek or desire friendships, relationships and intimacy, with some being or wishing to be sexually active (Brown and McCann, 2018; Whittle and Butler, 2018).

From a policy perspective, it is necessary to ensure that all children and adults with ID are able to access education regarding relationships and sexuality. In some areas, RSE programmes have been developed that are specific to the needs of people with ID. However, the issues of sexuality and its expression and the supports required must be more comprehensively and systematically reflected and integrated as a core element of education and health and social care policy (Baines et al., 2018; Barnard-Brak et al., 2014). Therefore, structured evidence-based RSE programmes need to be a core component of all education, health and social care initiatives. The starting point needs to be embedding RSE programmes within the school curriculum (Pound et al., 2017). To maximise ongoing impact and effectiveness, RSE programme delivery should be extended into adulthood as part of comprehensive service provision (Frawley and Wilson, 2016). This is necessary, given the clear evidence that people with ID are often socially isolated, lacking friendships and social networks and vulnerable to potential exploitation and harm (Gilmore and Cuskelly, 2014). Policy implementation has the potential to influence the opportunities for people with ID to form meaningful friendships and relationships. Without such opportunities, many will continue to remain unfulfilled in terms of their future relationship hopes and aspirations (Schaafsma et al., 2013).

There is a need to develop RSE programmes that engage with both the relationship and sexuality aspirations of the individual with ID by providing knowledge, information and creating networks of support (Barnard-Brak et al., 2014; Dukes and McGuire, 2009; Frawley and Bigby, 2014). People with ID usually live in the family home or in supported living settings, often requiring services and supports from education, health and social care services. However, evidence demonstrates that care and support can often be restrictive rather that facilitative (Gardiner and Braddon, 2009). There is a need therefore for practitioners within services and agencies to be self-aware and prepared to challenge prevailing attitudes, assumptions and stereotypes. This is necessary to fully meet the relationship and sexuality needs of people with ID while also addressing the concerns of parents and families (Brown and McCann, 2019). Therefore, practice needs to be informed by anti-discriminatory, inclusive, person-centred approaches (Department of Health, 2009; Scottish Government, 2013). Families are often concerned about the risk of personal safety, abuse, exploitation and harm of their family member with ID, further supporting, not diminishing, the need for education and support. The concerns, however, can lead to over-protection and sometimes excessive control that may inadvertently further limit life opportunities for the person with ID. An essential element of professional practice therefore needs to address concerns regarding protection, safeguarding and capacity to consent to sexual relationships and the positive benefits of participating in RSE programmes (Goli et al., 2018). This is necessary as practitioners delivering RSE programmes need to respond to the potentially conflicting tensions between the need to protect versus freedom of choice and the right to self-determination (Fisher et al., 2016).

From a practice perspective, practitioners across different services and agencies need to be aware that some people with ID will require additional time, resources and support to enable their individual relationship and sexuality needs to be comprehensively and accurately addressed (Finlay et al., 2015). By responding to these issues, RSE programme content and delivery should be co-produced and person-centred, thereby aiming to situate people with ID at the centre of the process (Frawley and Bigby, 2014). In addition, practitioners within their day-to-day roles need to recognise the relationship and sexuality aspirations of people with ID and respond effectively to their education and information needs (Frawley and Wilson, 2016). For this to become a reality, it may be necessary to support collaborative work between agencies and organisations such as schools, care organisations, day care providers, sexual health services and specialist ID health services (Baines et al., 2018; Barnard-Brak et al., 2014; Dukes and McGuire, 2009). As part of the service models within schools and day service provision, RSE programmes need to be provided for children, young people and adults with ID by practitioners with the knowledge, skills and confidence to facilitate effective delivery (Garwood and McCabe, 2000; Hanass-Hancock et al., 2018). To address these issues, there are opportunities for professional education and continuing professional development (CPD) programmes to integrate relationship and sexuality issues as a core element of the curriculum and staff development and the role of RSE programmes (McCann and Brown, 2018).

Some people with ID are sexually active and some may wish to be. People with ID want access to more information that will enable them to make decisions regarding forming and maintaining relationships and sexual intimacy. Participation in RSE programmes can have positive benefits for people with ID including improved decision making, sexual knowledge and safety, self-esteem and rights and responsibilities (Dukes and McGuire, 2009; Gardiner and Braddon, 2009; Garwood and McCabe, 2000). This is important as evidence already exists demonstrating the barriers to accessing appropriate information and healthcare (Whittle and Butler, 2018). Given concerns regarding HIV, STIs, unintended pregnancy and family planning, these are critical areas that need to be responded to if this population is not to be further disadvantaged. As a result, there is an opportunity for RSE programmes that fully address sexual health concerns, in a way that is accessible and

sensitive to the distinct needs of people with ID. RSE programmes therefore need to promote autonomy and informed decision making and also effectively challenge paternalism, stigma and discrimination, if supporting fulfilling relationships and promoting fully the expression of sexuality to be realised (McCann et al., 2016).

Future research

This systematic review presents an analysis and synthesis of the existing research evidence presenting the subjective views and experiences of people with ID regarding their participation in RSE programmes. The studies included in this review were undertaken using different research methods including qualitative designs, utilising focus groups and individual interviews. The other studies used quantitative designs, utilising questionnaire and survey methods. One study used a mixed-method design. There were no controlled trials or intervention outcome studies. There was no multi-centre, international or longitudinal studies examining the impact and outcome of participating in an RSE programmes. Therefore, it is not possible to determine the extent to which knowledge acquisition has influenced long-term behaviour change, for example, by the establishment of relationships and a reduction in HIV, STIs and unintended pregnancies. Consequently, future research priorities in this area should focus on systematically identifying and evaluating existing RSE programmes to determine a range of key factors including the underpinning theoretical models, programme structure, content and qualitative and quantitative outcome measures (Pound et al., 2017). This is necessary to be able to clearly establish what might constitute the gold standard and the long-term effectiveness of RSE programmes for people with ID. There is scope also to undertake research studies that are multi-centred to enable larger samples with a national, international and transcultural focus. By addressing these issues, it will be possible to confirm the effectiveness of a theoretically driven, structured RSE programme that is specific to the distinct needs of people with ID and their families and carers.

Strengths and limitations of the review

This review has identified that people with ID are accessing RSE programmes and appear to find them helpful; however, further research is required to investigate the extent to which they impact long-term behaviour change that enables the development of sustainable relationships and reduces the unintended consequences of being sexually active. Further limitations exist due to the quality of some of the study designs and small sample sizes, thereby impacting on the ability to apply the findings more widely.

Conclusion

There is well-established evidence that some people with ID have limited knowledge and skills regarding relationships and sexuality issues. This impacts on an individual's ability to establish or maintain relationships and to access the necessary social networks and supports, potentially leading to social isolation and loneliness. People with ID can experience health concerns such as STIs and other unintended consequences in keeping with the non-ID population. From the available evidence, RSE programmes appear to be useful and acceptable to people with ID. Furthermore, parents and families play an important part in the lives of their family member with ID, and they too have education and support needs that may enhance their understanding and response to their family members expression of sexuality. If the expression of a person's sexuality is a basic human right for all, any RSE programme needs to be consistently and comprehensively designed, developed and delivered in partnership with people with ID and their parents and families. Further

research is required to determine content, accessibility and acceptability and the benefits and long-term outcomes of RSE programmes on the lives of people with ID.

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Research in Developmental Disabilities

The experiences and support needs of people with intellectual disabilities who identify as LGBT: A review of the literature

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ABSTRACT

Background: People who identify as lesbian, gay, bisexual and transgender (LGBT) can face many challenges in society including accessing education, care and support appropriate to individual needs. However, there is a growing and evolving evidence base about the specific needs of people with intellectual disabilities (ID) in this regard.
Aims: The aim of this review was to explore the experiences of people with ID who identified as LGBT through an examination of studies that addressed their views and highlighted specific issues, concerns and service responses.
Methods and procedures: A comprehensive search of relevant databases from February 1995 to February 2015 was conducted. Studies were identified that met specific criteria that included: empirical peer reviewed studies, the use of recognised research methods and focused on people with ID whom identified as LGBT. The search yielded 161 papers in total. The search was narrowed and 37 papers were screened using rigorous inclusion and exclusion criteria. Finally, 14 papers were considered suitable for the review.
Outcomes and results: The data were analysed and key themes identified that included accessing health services, gender and sexual identity, attitudes of people with ID regarding their LGBT status, and education, supports and therapeutic interventions.
Conclusions and implications: There is a need for service providers and carers to be more responsive to the concerns of people with ID who identify as LGBT to improve their health and well-being by reducing stigma and discrimination and by increasing awareness of their care and support needs. The implications are discussed in terms of policy, education, research and practice developments.

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What this paper adds?

There is a growing and evolving empirical evidence base regarding the experiences of people who identify as LGBT and have an ID. This paper raises many important issues that have been gleaned from research studies that sought to gain different viewpoints and establish the needs of LGBT people with an ID. The discussion highlights issues relevant to future research, practice, educational and policy initiatives and provides useful recommendations around socially inclusive practice.

1. Introduction

The evidence base regarding the experiences and views of people with intellectual disability (ID) who identify as lesbian, gay, bisexual and transgender, their support needs and service provision, is growing and evolving. Policy makers worldwide have attempted to address some of the issues in policies, reports and best practice guides related to the equality and human rights agenda (Department of Health, 2009a; Health Service Executive, 2009; Scottish Government, 2013; World Health Organization, 2015). From a health perspective, people with ID experience a range of physical and mental health conditions that are more common than those experienced by the general population and requires access to health services (Kwok and Cheung, 2007; Young, Chesson, & Wilson, 2007). Physical health conditions such as epilepsy, respiratory disorders, gastric disorders, sensory impairments, cardiovascular disease and diabetes are common, as is mental illness by way of anxiety disorders, depression, bipolar disorder, schizophrenia and dementia (Emerson & Baines, 2010; McCarron et al., 2011). However, despite identified higher health needs and poorer health, as a population, they experience barriers to accessing health services appropriate to the individual physical and psychosocial needs, with significant consequences to their health and well-being (Alborz, McNally, & Glendinning, 2005; Brown, Duff, Karatzias, & Horsburgh, 2011). Furthermore, issues related to communication associated with cognitive impairment are common within the intellectually disabled population. The situation is further compounded by the ability of some to provide informed consent to treatment and further contributes to their disadvantage and acts as a potential barrier when seeking access to healthcare systems (Department of Health, 2009b; Boardman, Bernal, & Hollins, 2014). All of these issues provide distinct challenges to people with ID who identify as LGBT (Stoffelen, Kok, Hospers, & Curfs, 2013).

LGBT people with ID are often subjected to what is acknowledged as 'layered stigma'. People with ID may experience stigma and discrimination as a result of their disability and impairments and because of their LGBT status (Bennett & Coyle, 2001), resulting in 'minority stress' (Meyer, 2003). Prejudice and discrimination may create further marginalisation, social exclusion, and limit the opportunity for developing meaningful relationships (Hall, 2010). This is particularly the case for people with more severe and complex ID (Mansell, 2010). In terms of psychosocial wellbeing, existing studies demonstrate that LGBT people in the general population experience more psychological distress than heterosexuals and are at greater risk of mental health problems (King et al., 2008; Meyer, 2010). Issues for concern include institutionalized prejudice, social stress, social exclusion, homophobic and transphobic hatred, bullying, and violence (David & Knight, 2008; Kuyper & Fokkema, 2011). There can be an increased susceptibility to alcohol and drug misuse as well as suicidality and issues related to self-harm (Cochran, Sullivan, & Mays, 2003; Grant, Mottet, & Tanis, 2011). In one study, Mayock, Bryan, Carr, Kitching (2009) reported that 86% of the LGBT participants surveyed experienced depression at some point in their lives, with 25% taking prescribed medication, and 27% indicating that they had self-harmed at least once in their lives. However, many people developed resilient traits through experience that often strengthens their personal sense of well-being and quality of life (McCann & Sharek, 2014). Across the developed world there has been a shift away from institutional models of care to care in the community (Department of Health, 2009a; Scottish Government, 2013). With this move, the extent

Table 1
CINAHL search strategy and results.

Search code	Query	Results
S1	intellectual disab*	8439
S2	mental retard*	1229
S3	mental deficiency	15
S4	mental handicap	59
S5	developmental disab*	4122
S6	homosexual*	5122
S7	gay	2585
S8	lesbian*	1981
S9	bisexual*	1819
S10	transgender*	1099
S11	transsexual*	511
S12	intersex	73
S13	queer	160
S14	LGBT	249
S15	S1 OR S2 OR S3 OR S4 OR S5	12538
S16	S6 OR S7 OR S8 OR S9 OR S10 OR S11 OR S12 OR S13 OR S14	7726
S17	S15 AND S16	25

of the health inequalities experienced by people with ID has become increasingly apparent. As a result of their extended life expectancy and multi-morbidities, people with ID are high and frequent consumers of all healthcare services and the need to ensure that there is equality of access to universal health services and the provision of specialist ones when needed (Maulix, Mascarenhas, Mathers, Dua, & Saxena, 2011; Scottish Government, 2013).

Despite the growing evidence base of the extent of their health needs and the positive moves arising from care located in the community, many continue to experience stigma, discrimination, social disadvantage and poor health (World Health Organization, 2013). Today, many people with ID live relatively independently in the community, some in the family home, some may receive visiting social care support or others in 24 h staffed accommodation (Prime Ministers Strategy Unit, 2005; Department of Health, 2009a; Scottish Government, 2013). Whilst individual social care support needs may be addressed, it is evident that some family carers and social care support workers lack knowledge of the health conditions experienced by people with ID that adversely impacts on healthcare provision necessary for early identification and treatment options (Elderton & Jones, 2011).

2. Method

2.1. Research questions

The aim of this review is to establish the views and experiences of people with ID who identify as LGBT and highlight issues that may guide future policy, education, supports and service provision. To address these aims, two questions were posed in this review of the literature:

1 What are the views and experiences of service users who have ID and identify as LGBT?
2 What are the policy, education, support and service responses necessary for people who have ID and identify as LGBT?

2.2. Search and selection strategy

An expert subject librarian was consulted. The systematic search of available studies was carried out using the following databases: CINAHL, MEDLINE, PsycINFO, PubMed and Sociological Abstract. A search strategy was developed using the Boolean operators AND/OR within the following search string: intellectual disab* OR mental retard* OR mental deficiency OR mental handicap OR developmental disab* AND homosexual* OR gay OR lesbian* OR bisexual* OR transgender* OR transsexual* OR intersex OR queer OR LGBT. An example of the search strategy and results of one database is provided (Table 1) and this was applied to all of the other identified databases.

The searches resulted in 161 combined hits across the databases. The search outcomes are set out in Fig. 1. All of the 161 papers identified were reviewed for their relevance; 37 titles and abstracts were reviewed against the inclusion criteria. The inclusion criteria were limited to academic journals, peer reviewed empirical studies and written in English. Studies had to focus specifically on the aims of the review by clearly highlighting the views and experiences of people with ID who identify as LGBT and the carer and service responses pertinent to their needs. Those papers that did not meet the criteria were excluded from the review. A hand search was also undertaken of the reference lists of the identified papers leaving a total of 14 papers for full review. The data were accessed from February 1995 to February 2015. Studies that used a qualitative, quantitative or mixed methods approach were considered for inclusion in the review.

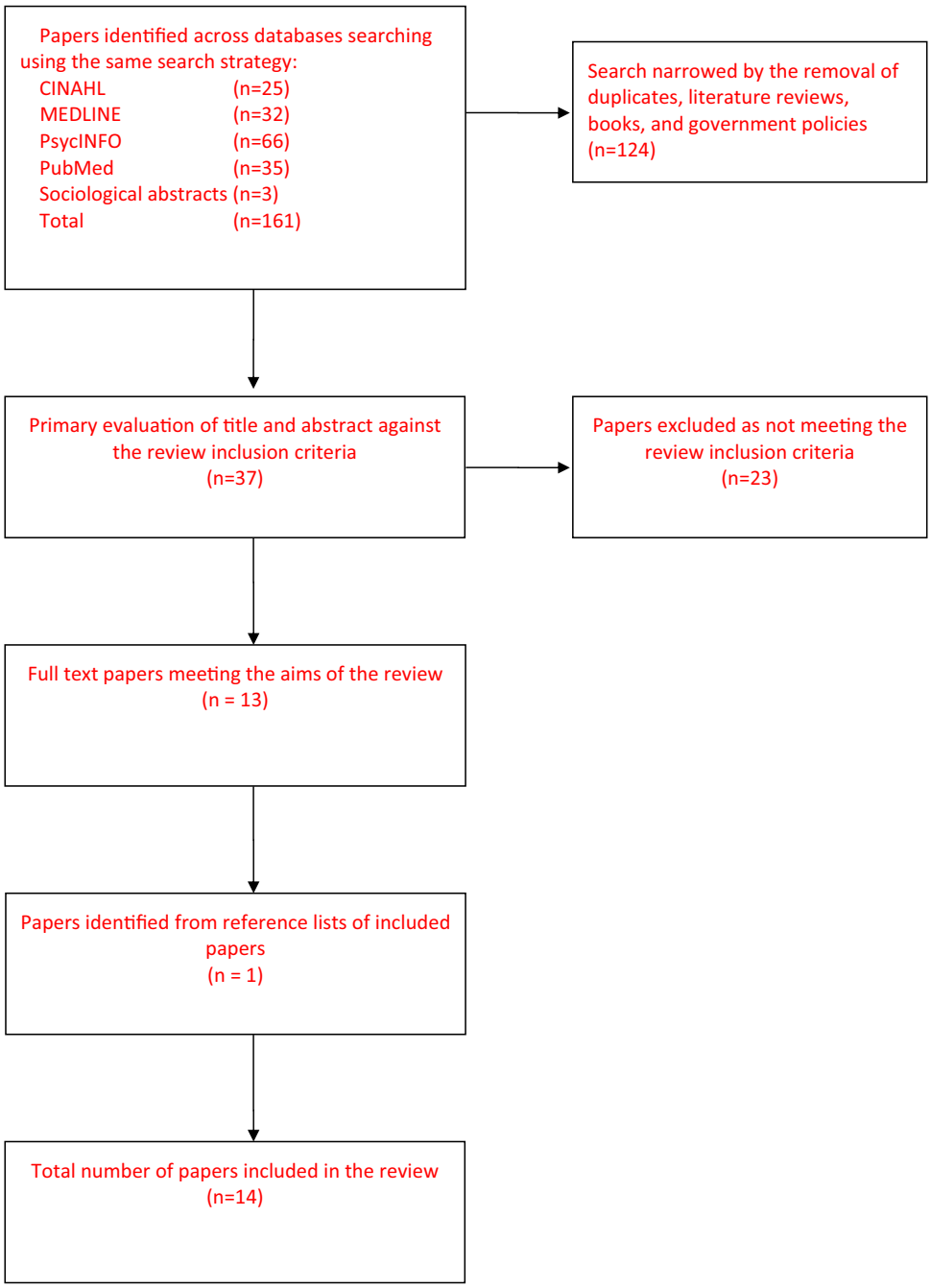

Fig. 1. Identification, retrieval and inclusion of relevant studies.

2.3. *Quality assessment*

Following identification of the studies the Critical Appraisal Skills System (Critical Appraisal Skills Programme, 2013) was used to provide an evidence-based framework to reviewing the papers and consistently applied the essential questions to each of the selected studies (Table 2). Similar to the approach used by Rushbrooke, Murray, and Townsend (2014), each CASP question was scored zero, one or two out of a possible total of twenty points. A score of zero was given if the article contained no information, a score of one indicated a moderate amount of information and a score of two demonstrated that the article fully addressed the relevant question. A total of 6 out the 14 studies received a score of 17 or more highlighting the overall quality of each study (Abbott & Burns, 2007; Burn & Davies, 2011; Löfgren-Mårtenson, 2009, 2012; Parkes, Hall, & Wilson, 2009; Stoffelen et al., 2013). However, from a quality perspective, 6 studies received a CASP score ranging from

Table 2
CASP quality scores.

CASP criteria	Abbott & Burns (2007)	Abbott & Howarth (2007)	Bedard et al. (2010)	Burns & Davies (2011)	Cambridge (1996)	Edmonds & Collins (1999)	Elderton et al. (2014)	Löfgren-Mårtenson (2009)	Löfgren-Mårtenson (2012)	McClelland et al. (2012)	Parkes et al. (2009)	Stauffer-Kruse (2007)	Stoffelen et al. (2013)	Withers et al. (2001)
1. Clear statement of aims	1	1	1	2	2	0	2	2	2	2	2	1	2	2
2. Appropriate methodology	2	2	2	2	2	1	2	2	2	2	2	1	2	2
3. Appropriate research design	2	2	1	2	2	1	2	2	2	2	2	1	2	2
4. Appropriate recruitment strategy	2	2	1	2	2	1	2	2	1	1	2	1	2	1
5. Appropriate data collection methods	2	2	2	2	1	1	2	2	2	2	2	1	2	2
6. Research relationships considered	1	1	1	1	1	1	1	2	2	1	1	1	1	1
7. Consider ethical issues	1	1	1	1	0	1	1	1	2	0	2	0	2	1
8. Rigorous analysis	2	2	2	2	2	0	1	2	2	1	1	0	2	2
9. Clear findings	2	1	2	2	2	1	1	2	2	1	2	1	2	1
10. Value of the research	2	1	2	2	2	1	1	2	2	2	2	1	2	2
Total scores out of 20	17	15	15	18	16	8	15	19	19	14	18	8	19	16

14 to 16 from a possible 20, indicating a lack of rigor in areas including appropriate data collection methods, research relationship considerations, ethical issues and the clarity of the findings (Abbott & Howarth, 2007; Bedard, Zhang, & Zucker, 2010; Cambridge, 1996; Elderton, Clarke, Jones, & Stacey, 2014; McClelland et al., 2012; Withers et al., 2001). These are issues that need to be addressed in future research studies thereby seeking to improve the overall quality of the available research evidence. Two papers adopted case study designs (Edmonds & Collins, 1999; Stauffer-Kruse, 2007) and received CASP quality scores of 8 respectively, primarily due to limited information related to study aims, recruitment, methods, ethics, analysis and findings which adversely affected the overall value of the research. However, the case studies highlight important issues in relation to the topic and the complexities involved in providing care and support for some people with ID. Following review, using the CASP, all papers (n = 14) were deemed relevant to the aims of the review.

2.4. Characteristics of the selected studies

The 14 studies that addressed the review questions are presented in Table 3. The majority of the studies (n = 9) were carried out in the United Kingdom (UK), two studies were conducted in Sweden, two in Canada and one in the Netherlands. The selected studies had sample sizes ranging from single case studies to 71 participants involving people with ID, families and paid carers. A total of 11 studies used qualitative methods, including one-to-one interviews, focus groups and case studies (Abbott & Burns, 2007; Abbott & Howarth, 2007; Edmonds & Collins, 1999; Elderton et al., 2014; Löfgren-Mårtenson, 2009, 2012; McClelland et al., 2012; Parkes et al., 2009; Stauffer-Kruse, 2007; Stoffelen et al., 2013; Withers et al., 2001). Three studies used a quantitative approach (Bedard et al., 2010; Burns & Davies, 2011; Cambridge, 1996). The reviewers adopted a pragmatic approach by including studies using different methodological approaches in order to allow for a fuller understanding of the diverse range of issues.

2.5. Data extraction and analysis

The review process was guided by recognised methods involving the synthesis of mixed literature (Mays, Pope, & Popay, 2005). The papers were analysed in the following ways. Initially, all themes relevant to the research questions were identified and coded from the results section of the papers. The identified themes were then grouped according to concepts to allow for comparison between themes both within and between each study. The themes were subsequently considered by the review team for verification and agreement.

3. Findings

Following analysis, five main themes were identified: (i) accessing and using services, (ii) gender and sexual identity, (iii) attitudes of people with ID regarding their LGBT status, (iv) sexual risk behaviours, (v) education, supports and therapeutic interventions.

3.1. Accessing and using services

In terms of engagement with health services and barriers to access, two studies specifically explored staff attitudes towards people who are LGBT and have an ID. Abbott and Howarth (2007) undertook a qualitative study involving interviews with staff (n = 71) to determine the supports available to service users in their care and found that most staff lacked confidence in discussing sexuality issues, possessed poor attitudes and needed education and training regarding the needs of people with ID. The second qualitative study, conducted in Sweden with a sample of n = 37 comprising people with ID, their paid carers and families, revealed discriminatory attitudes, safety and vulnerability issues and a lack of guiding policies in terms of adult protection, sexual health and ID. The findings also identified a 'blind spot' regarding the expectations and visibility of people with ID when accessing heath services relevant to their sexual health needs and the need for the development of more inclusive strategies (Löfgren-Mårtenson, 2009).

Both studies identified the need for staff training as well as organizational support for future practice developments that would address knowledge, skills and attitudes. In a review of 13 case records of people with ID undertaken by Parkes et al. (2009) in the UK, distinct physical and psychosocial challenges were identified for transgender people with ID around mental health concerns, tackling stigma and discrimination and accessing and using the extremely limited available services.

3.2. Gender and sexual identity

Whilst several studies addressed LGB experiences related to this theme, fewer explored issues relevant to people who identify as transgender. In the Swedish study, participants referred to the 'invisibility' of people who are LGBT and have an ID and issues around expressing and appreciating the rich variety of gender and sexual experiences that exist (Löfgren-Mårtenson, 2009). In a UK study, staff alluded to the presumed 'asexual' status of people with ID (Abbott & Howarth, 2007). In contrast, positive traits were experienced by service-users such as resilience, confidence building, self-affirmation and self-acceptance in the UK study involving 10 men and 1 woman with ID (Elderton et al., 2014). Two studies, one undertaken in the UK (Parkes et al., 2009) and the other in the Netherlands (Stoffelen et al., 2013), identified significant traumatic life

Table 3
Papers included in the review.

Study Citation and Country	Aims	Sample	Data collection method	Key Findings	Recommendations	CASP scores out of 20
Qualitative studies (n = 11)						
Abbott & Burns (2007) UK	Explore same sex relationships of people with ID.	71 staff in 20 ID services. 9 women and 11 men with ID	Semi-structured interviews.	Themes included: talking about love, reluctance to come out, discrimination, social isolation, lack of support and staff responses.	Recognition of issues and needs. Supports required with intimate relationships. Power differential held by paid staff. Appropriate organizational responses.	17
Abbott & Howarth (2007) UK	Elicit staff views on supporting LGB people with ID around intimate relationships.	71 staff in 20 ID services.	Individual interviews.	Most staff lacked confidence in discussing sexuality issues. Poor staff attitudes. No policies or training.	Develop appropriate policies. Staff education and training. Management support. Affirmative practices.	15
Edmonds & Collins (1999) UK	Examine the supports for a gay man with ID to explore his sexual identity.	One case study.	Case study.	Outcomes were reported in several areas: sexual health, condom use, legal issues, consent, emotions, rights and family issues.	Community supports are identified. Training for service providers required.	8
Elderton et al. (2014) UK	Explore strategies to help LGBT people with ID strengthen self-identities.	10 men and 1 woman with ID	Narrative Therapy-based workshops	People able to discuss being LGBT, positive stories of being gay, negative experiences such as abuse, homophobic assaults, sexual exploitation & bereavement. Resilience.	Further research comparing narrative-based group approaches to other group approaches.	15
Löfgren-Mårtenson (2009) Sweden	Explore the invisibility factors of younger LGB people with ID	13 young people and adults with ID, 13 support staff 11 parents.	Qualitative 1:1 interviews.	The reporting of people with ID as LGBT was uncommon across participant groups. People with ID and who are LGBT was viewed by support staff as a further deviation. Limited accessible resources available regarding LGBT issues for people with ID.	Challenging heterosexual assumptions. Sexuality and ID reflected as a research issue.	19
Löfgren-Mårtenson (2012) Sweden	Determine the views of young people with ID and sex education provision.	16 people with ID aged 16–24 years.	Qualitative 1:1 interviews.	Restricted education focused on sexual risks. Need to consider pleasure, desire and intimacy.	Challenge heteronormativity within special schools. Review pedagogical approaches.	19

Table 3 (*Continued*)

McClelland et al. (2012) Canada	Explore sexual health risks and supports to younger LGBT people with ID.	10 young people aged 17–26 years with ID.	Qualitative interviews and focus groups.	Challenges to autonomy. Having unsafe sex in unsuitable spaces. Negative sexual health outcomes.	Increase dialogue and support. More information that is accessible, relevant and useful. Policies to support LGBT rights and advocacy initiatives.	14
Parkes et al. (2009) UK	Determine the features of people with ID who have 'gender dysphoria' or cross dress	13 people with ID.	Retrospective review of anonymised data from clinical case records	High level of mental health issues. Gender identity issues similar to those without ID. Longer assessments and psychotherapeutic work before considering hormone and surgical interventions.	Further research is needed to identify options for supporting people with ID with gender dysphoria who cross-dress to reduce stigma and enable acceptance of the individual's identity.	18
Stauffer-Kruse (2007) UK	Examine the experiences of gay men with ID and sexual identity issues.	One case study.	Case study	Need to educate gay men with ID about their sexuality and sexual identity. LGBT community projects may enable joint working to help GMID to identify with the gay community; ethical issues around the possible vulnerability of GMID.	Care staff need to explore the rights of GMID to take risks and the implications of being a GMID. Increased access to psychosocial supports.	8
2013 Netherlands	Examine the experiences of gay men and women with 'mild' ID.	21 people with a 'mild' ID	Semi-structured interviews.	Almost half of the participants ($n = 10$) reported that they had experienced sexual abuse including partner violence ($n = 6$). They also that there was a lack of support for gay people with an ID.	High prevalence of negative sexual experiences, the lack of support, training and sex education.	19

Withers et al. (2001) UK	Evaluate a support group for men with IDs who have sex with men.	Group members (n = 5)	Group interview.	Issues including safety, contact with 'gay culture,' self-labelling as 'gay,' and societal attitudes towards gay people. Good group experiences and positive supports.	Empowering and user-led where participants made a useful comments and recommendations. Need to include baseline data of participants' knowledge and behavior in future research.	16
Quantitative studies (n = 3):						
Burns & Davies (2011) UK	Examine attitudes towards homosexuality and gender roles in women with ID.	27 women with ID in two NHS Trusts.	Three self-report measures.	Limited knowledge about homosexuality. Hold prejudicial beliefs. Gender beliefs associates with negative attitudes toward homosexuality.	Education focusing on flexibility of gender roles and more positive attitudes towards homosexuality.	18
2010 Canada	Investigate different gender identities and sexual orientations of people with developmental disabilities.	16 men and 16 women with ID	1. Gender Identity Questionnaire 2. Sexual History Questionnaire 3. Erotic Response and Orientation Scale 4. Recalled Childhood Gender Identity/Role Questionnaire.	A total of 87% identified as heterosexual (87%), (9.7%) as bisexual or questioning (3.2%), were interested in same sex partners. Four people indicated that they had gender identity dysphoria (GID).	It is good practice for professionals to identify uncertainty about gender and sexuality issues due to social and life experiences, especially around abuse and limited information and education.	15
Cambridge (1996) UK	Investigate the prevalence of men with ID who have sex with men in public places	Men with ID in three London Boroughs (26 services).	Survey.	13 services from 26 where there is a management or practice issue. Risks of HIV and sexual and emotional exploitation.	HIV prevention work and sexual health promotion. Education and training days for staff and service users. Policy developments.	16

events and challenges faced by participants including childhood abuse, sexual abuse, physical assault and partner violence, highlighting the need for recognition of the existence of such issues within the population of people with ID who identify as LGBT and the provision of individualized assessment, therapy, treatment and support. In one study, exploring gender identities and sexual orientation, where 4 participants experienced gender dysphoria, practitioners were encouraged to explore gender and sexuality issues. The authors concluded that psychosocial supports should be available to all people with ID whom identify as LGB and T (Bedard et al., 2010).

3.3. Attitudes of people with ID regarding LGB status

In a quantitative study undertaken in the UK involving 27 women with ID, their attitudes towards people who identified as LGB were explored. The findings found that almost three quarters (74%) of respondents lacked knowledge of LGB issues and a majority (70%) held negative beliefs and attitudes towards people who are LGB (Burns & Davies, 2011). In contrast, in the case study undertaken by Edmonds & Collins (1999) in the UK, positive experiences were identified, such as, self-acceptance and self-affirmation in relation to a person's LGB identity. In the Swedish study undertaken by Löfgren-Mårtenson (2009) participants expressed unhappiness and difficulty accepting their gay identity and were perceived by staff as possessing another 'deviation' and an additional unnecessary disability.

3.3.1. Invisibility

Sexuality concerns are often ignored by service-providers with participants stating that they were made to 'feel invisible' in relation to their gay identity (Stauffer-Kruse, 2007; Stoffelen et al., 2013). Six studies (Abbott & Burns, 2007; Abbott & Howarth, 2007; Burns & Davies, 2011; Cambridge, 1996; Edmonds & Collins, 2007; Stoffelen et al., 2013) identified the need for and the importance of the education of people with ID about sexual practices, risks and forming and maintaining intimate relationships and the need for education and practice development for families and staff involved in their care and support. These aspects were seen in the context of equality, empowerment and social inclusion. In one study involving interviews with 20 people with ID, participants were encouraged and very able to articulate their thoughts and feelings about sexuality issues including coming out, staff and family responses to sexual concerns, intimacy and future hopes and dreams (Abbott & Burns, 2007). Study recommendations included more inclusive and LGB affirmative practices and appropriate staff education and training.

3.4. Sexual risk behaviours

In a quantitative study undertaken by Cambridge (1996) in the UK, investigating 'risky'sexual behaviours among men who have sex with other men, the findings indicated that a significant number of participants (90%) had sex with other men with an ID and that three quarters (75%) had engaged in 'risky' sexual activities. Nearly one third (33%) of the study participants had been sexually abused. The author recommends education and training for people with ID and their families and paid carers. The findings also identified the need for the development of guiding policies that take into account safety and vulnerability factors faced by men with ID who have sex with other men and highlighted the need for the development of accessible and targeted resources tailored specifically to the needs of men ID who are LGBT.

3.5. Education, supports and therapeutic interventions

The issue of supports and therapeutic interventions for people with ID and support for families and paid carers was a theme identified in five of the studies included in this review (Abbott & Burns, 2007; Abbott & Howarth, 2007; Stauffer-Kruse, 2007; Withers et al., 2001). In the qualitative study undertaken by Withers et al. (2001) in the UK of a support group for men with ID who have sex with other men, the main issues highlighted were sexual identity, sexual health and mental health, including depression, anxiety and suicidality. All participants found the group helpful and liked that it was service-user led, supportive and empowering. The recommendations arising from the study were improving supports to families and paid carers through education initiatives and peer support groups, with increased access to talking therapies and specific LGBT support networks and the identification of sexual knowledge and behaviours of LGBT men with ID. In terms of educational initiatives, one study conducted in Sweden identified issues related to heteronormative assumptions that increases the invisibility or further marginalisation of 'gay' people with ID (Löfgren-Mårtenson, 2012). The interviews revealed that the sexual experiences of people with ID tended to focus on sexual risks rather than encouraging and supporting dialogue around pleasure, desire and intimacy. Abbott & Howarth (2007) and Abbott & Burns (2007) identified the need for service managers to provide support for staff in their organisations when working with service users with ID who are LGBT, with Parkes et al. (2009) focusing more specifically on the support needs of people with ID with gender dysphoria and who cross-dress. From the perspective of psychological support, Stauffer-Kruse (2007) identified the need for developments in this area for gay men with ID. Given the range of mental health and psychological issues that can be experienced by people with ID and notably gay men with ID, there is a need to focus on developing services appropriate to their needs.

Table 4
Areas for further research involving LGBT people with ID.

- Evaluation and impact of the profile of people with ID within Government policy
- National and international multi-centre studies
- Transcultural studies
- Epidemiological studies
- Evaluation of interventions focusing on sexual health assessment, treatment and management
- Evaluation of psychological and support interventions
- Evaluations of the impact and effectiveness of education and training programmes
- Studies with a specific focus on the needs of Lesbians and Transgender people with ID

4. Discussion

The review has highlighted key issues for people with ID who identify as LGBT in terms of specific health and social care needs. The findings highlight challenges in terms of further research, policy, education and practice developments.

4.1. Research

It is evident from this review of the literature that there is a requirement for a sustained and specific research-focus on the needs of people with ID who identify as LGBT to further identify support mechanisms, interventions and service responses that meet their distinct needs. Developing the evidence-base in this area is important given the significant changes that have taken place over the recent decades with regards to the move away from institutional to community-based models of care and the wider social inclusion of people with ID. When coupled with the developments and changes in the lives of LGBT people in general by way of their Human Rights and equality, the needs of people with ID require attention. The majority of the studies that formed this review were undertaken using qualitative (n = 11) designs, employing one-to-one interviews, focus groups and case studies. The remaining studies (n = 3) used quantitative surveys; there were no mixed method studies.

There was an absence of intervention and evaluation studies. The samples sizes across all the studies ranged from single case studies (Edmonds & Collins, 1999; Stauffer-Kruse, 2007) through to a sample of n = 71 in the study involving individual staff interviews by Abbott & Howarth (2007). The studies tended to focus on gay men with ID and there was a limited focus on lesbians and transgender people with ID. There was an absence of epidemiological studies and only one evaluation study focusing on a support group for gay men with ID (Withers et al., 2001). There were no multi-centre national or international studies or longitudinal studies and no policy analysis studies examining how the needs of LGBT people with ID have or are being addressed and analyzing the impact and outcomes of policy. There are therefore important gaps that need to be addressed in the understanding of the needs of people with ID and how they can be more effectively met in the future. Table 4 sets out opportunities for further research on LGBT people with ID.

The importance of education and training was recognised in six studies (Abbott & Burns, 2007; Abbott & Howarth, 2007; Burns & Davies, 2011; Cambridge, 1996; Edmonds & Collins, 1999; Stoffelen et al., 2013). Further enquiry is therefore needed on the effectiveness and impact of education and training provided for people with ID, their families and carers and practitioners, with an opportunity to undertake pre and post evaluation studies of education and training, thereby measuring longer term outcomes and their benefits. Given the health inequalities and high health needs of people with ID and the issues related to abuse and mental illness identified in this review, there is a need to research the effectiveness of treatments and interventions in areas such as the treatment of HIV and psychological interventions for mental illness, trauma and abuse and individual and family support. Another important limitation of the studies included in this review is their relatively small sample sizes. There is therefore scope to undertake studies that are multi-centred to enable larger samples with a national, international and transcultural element.

4.2. Policy development

There have been significant changes and developments in recognising the human rights of LGBT people, and legislation to prevent discrimination exists in many countries worldwide (World Health Organization, 2013). With these developments is equality and freedom to express a gay identity and sexual behaviours; for some this can be a difficult and complex process (Kuyper & Fokkema, 2011; McNeil, Bailey, Ellis, Morton, & Regan, 2012). From this literature review, it is apparent that this is often the case for people with ID who identify as LGBT. While specific ID policy has been developed in many countries that have influenced the move to community living, the issue of their sexuality and in particular those who are LGBT has attracted limited attention (Equality Authority, 2002; Coleman et al., 2011; Department of Health, 2013; Scottish Government, 2013). Given the body of evidence regarding their health inequalities and health needs, this is a gap that needs to be addressed, including those related to sexual health (Health Service Executive, 2009; Emerson & Baines, 2010). Concerns may exist from families and support workers due to the cognitive impairment experienced by people with ID and issues related to their vulnerability, capacity and consent and concerns regarding exploitation and abuse. Acknowledging child and adult protection

concerns which on one hand seek to protect individuals from harm and on the other enabling independence so people with ID can express their sexuality and experience sexual relationships is necessary. In some countries, specific legislation and policy is in place to better support vulnerable adults at risk of harm and abuse (World Health Organization, 2015), and for specialist Intellectual Disability Services to support mainstream sexual health and social care services to provides access to specialist capacity assessment, and supports for LGBT people with ID and more complex care needs (Slevin, McConkey, Truesdale-Kennedy, Barr, & Taggert, 2007; Slevin, Truesdale-Kennedy, McConkey, Barr, & Taggart, 2008).

Arising from this review is the need to ensure that sexual health and ID policies take account of and reflect the sexual health needs of people with ID. This requires policy responses to ensure that services take account of their care and support needs and can make reasonable adjustments to ensure equal access that recognizes that some people with ID may also be LGBT (World Health Organization, 2013). Intellectual Disability- specific policy needs to ensure that the sexual needs of people with ID are reflected so that specialists work collaboratively with sexual health practitioners in areas such as shared assessments, the provision of psychological therapies, advising on capacity and consent issues and enabling sexual health information to be presented in an accessible format and that additional support is available to manage complex cases (Withers et al., 2001; Elderton et al., 2014). Acknowledging the potential presence of internalised homophobia by some people with ID and the existence of transphobia and to have in place strategies to support people (Meyer, 2003; Kuyper & Fokkema, 2011). Robust policy responses are necessary to ensure that double discrimination is addressed to prevent does prejudice towards people with ID and those are also LGBT, thereby avoiding further disadvantage.

4.3. Practice

It is necessary for all care services to recognize that people with ID can also be LGBT and that paternalism, heteronormativity, prejudice and negative attitudes may exist within organisations (Jukes & Aldridge, 2006; Gomes, 2012). Creating opportunities for practitioners to discuss issues such as sexual identity, LGBT relationships, and concerns about vulnerability in relation to exploitation and abuse is necessary if the aspirations of LGBT people with ID are to be realized (Boardman et al., 2014). Challenging negative attitudes and stereotypes from people with ID, families and practitioners is important to minimise the potential for double discrimination and stigma arising from the ID and LGBT labels (Kline & Preston-Shoot, 2012). Local policies therefore need to recognize that some people with ID may also be LGBT and reflect anti-discriminatory practice to promote equality, full social inclusion and Human Rights.

From a support perspective, the expression of sexual identity by people with ID will require additional time and resources. To achieve this, collaborative working and support across care services, sexual health services and specialist intellectual disability services will be necessary for some people with ID. From this review, it is evident that people with ID are sexually active; some are LGBT and some men with ID have sex with other men. There is evidence of 'risky' sexual behaviours and a need to ensure that sexual health needs are fully assessed, treatment provided and additional supports made available. Some LGBT people with ID experience mental illness such as depression and anxiety disorders, an issue reflected in the intellectual disability mental health literature (Whitaker & Read, 2006; Mental Health Commission, 2009). There is evidence of sexual abuse and partner abuse and services and practitioners need to be alert to the possibility and create opportunities to explore and discuss the issues with people with ID (Sequeria & Hollins, 2003; Cambridge, Beadle-Brown, Milne, Mansell, & Whelton, 2011). Access to specialist assessment, treatment and therapy for mental illness as well as access to therapy, effective in addressing distress and trauma related abuse may be needed (Department of Health and Children, 2006; Bhaumik, Gangadharan, Hiremath, Swamidhas, & Russell, 2011). Practitioners should promptly implement procedures to safeguard and protect the vulnerable from harm and ensure that appropriate support is available. An important role of practitioners is facilitating access to sexual health services and to local LGBT networks and support groups, such as those focusing on gay men's health. Collaborative working with LGBT community networks and support groups will enable LGBT people with ID to access mainstream LGBT services and to develop ID- specific services.

4.4. Education

LGBT people with ID require education and support, for example, to express their sexuality when adapting to their sexual identity. Families and support workers often have limited knowledge about the health of people with ID that may include their sexual health needs (Wark, Hussain, & Edwards, 2014). There should be access to education about being LGBT, sexuality and relationship concerns, and the opportunity to discuss pertinent issues regarding the LGBT person with ID. Induction programmes for practitioners in primary care, sexual health and support services should include areas such as the needs of people with ID, social inclusion and additional supports, LGBT sexuality issues, the role of specialist intellectual disability services, and local safeguarding and adult protection policies (Cambridge, 1996; Philips, Morrison, & Davis, 2004; Barr & Gates, 2008).

For practitioners in specialist intellectual disability services, there is an opportunity to undertake education and training with colleagues in sexual health services, thereby sharing knowledge and skills and developing an understanding about their services and how LGBT people with ID can be better supported (McMurray & Beebee, 2007; Burns & Davies, 2011). This will enable practitioners in specialist intellectual disability services to work in partnership with LGBT people with ID, their families and care services and provide assessment, treatments, interventions and supports that takes accounts of the needs of the population in a way that is person-centred and reasonable adjustments made (Jukes & Aldridge, 2006;

Turner & Robinson, 2011). Providing information in an accessible format is necessary on issues such as sexual identity, being LGBT, sexual behaviours, relationships and practices, sexual health and sexual health services, access to advice and support, safeguarding and adult protection.

4.5. Strengths and limitations of the review

There is an increased interest in the experiences and needs of people with an ID identifying as LGBT, and the evidence base continues to grow and evolve. This review has uncovered important concerns that can guide and inform policy, education, practice and the support needs of people with ID who identify as LGBT as part of the drive towards more socially inclusive and responsive care. In terms of available evidence, limitations exist due to the robustness of the study designs, which can be inherent in undertaking research with this population. While seeking to be rigorous in terms of the quality review process, the authors acknowledge potential subjectivity, and to address this, a recognised framework was applied consistently throughout. Furthermore, the primary focus of this review concerned the needs and experiences of people with ID who identify as LGBT; the authors recognize the established body of evidence around the concept of sexuality, however this was outside the scope of the current review and is an area that will require further attention.

5. Conclusion

It is apparent from the findings from this review that people with ID who identify as LGBT still face significant challenges in terms of their sexual expression and identity. In terms of human rights, social inclusion and equality initiatives, opportunities exist to better support the specific health and social care needs of people who identify as LGBT. Education initiatives targeting knowledge and skills development for service personnel as well as focusing on tackling discrimination and prejudice have been proposed. Government policies need to be inclusive, empowering and rights-based (Institute of Medicine, 2011; World Health Organization, 2013). LGBT people with ID are sexually active and their sexual health and support needs should be recognised and supported in ways that are person-centred, respects human rights and dignity, while being responsive to adult protection concerns. The provision of appropriate psychological interventions is an area requiring attention, as is the need for access to and development of social networks and support groups. Innovative approaches to quality supports and interventions should be available to this population and become the main focus for future research.

Conflict of interest

The authors declare no conflict of interest.

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Review article

Sexuality issues and the voices of adults with intellectual disabilities: A systematic review of the literature

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ABSTRACT

Background: There is a growing and evolving research evidence base regarding sexuality issues and adults with intellectual disabilities. Individuals can face challenges, including the right to express their sexuality and to access necessary education and supports.
Aims: This systematic review explores sexuality experiences, the views and opinions of adults with intellectual disabilities and highlights areas for future practice developments.
Methods and procedures: A comprehensive search of relevant databases from January 2006 to December 2016 was carried out. Included studies had to address specific criteria including: peer reviewed papers, the use of appropriate research methods, and focused exclusively on the individual views and opinions of people with an intellectual disability. The search of relevant databases yielded 230 hits. Following the application of explicit inclusion and exclusion criteria, 23 papers were deemed suitable for the review.
Outcomes and results: The data were analysed and key themes were identified that included: autonomy v's risk of harm, knowledge and sexuality, relationships and intimacy, self-determination and taking control, and encouragement and supports.
Conclusions and implications: Adults with intellectual disabilities need education and support to express their sexuality and to meet individual needs.

What this paper adds?

Studies on the topic tend to present the views and opinions of families, carers and professionals. This review highlights issues from the available research that address the unique experiences of adults who have an intellectual disability. The discussion presents areas relevant to policy, practice education and future research priorities.

1. Introduction

The expression of sexuality, including how individuals form and maintain intimate relationships, is a fundamental part of being human (Krebs, 2007; Matich-Maroney, Boyle, & Crocker, 2005; World Health Organization, 2013). In health and social care settings, practitioners are paying more attention to issues related to sexuality in terms of the provision of the necessary psychosocial supports and education (Greenhill & Whitehead, 2010; Gascoyne, McCann, Quinn, & Hughes, 2016; McCann, 2010; Palumbo, 2016). Another important consideration is the emancipatory or human rights position whereby people have opportunities to explore and make

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decision around how they live their sexual lives (Officer & Shakespeare, 2013). For some, the only boundaries around sexual expression are that they do not include coercive sexual acts and that the right to express ourselves sexually is measured against an individual's rights to privacy and autonomy (Gomes, 2012). The World Health Organization expands their conceptualisation and understanding of sexual health concerns thus:

> ….*the possibility of having pleasurable and safe sexual experiences, free of coercion, discrimination and violence. Indeed, it has become clear that human sexuality includes many different forms of behaviour and expression, and that the recognition of the diversity of sexual behaviour and expression contributes to people's overall sense of well-being and health* (World Health Organization, 2015, p4.)

Furthermore, enlightened ways of supporting people in their expression of sexuality is evidenced in the move from a purely biomedical position to a more person-centred and inclusive approach that places rights, choices and voices at the hub of all health and social care developments (Thomas et al., 2017). The changing landscape should encapsulate fundamental human rights and social inclusion directives that encourages and supports the expression of sexuality (McCarthy, 2014; Winges-Yanez, 2014).

Concerns about the expression of sexuality in people with intellectual disabilities is not new and one that has attracted significant attention in the past and remains a contentious issue (Aunos & Feldman, 2002; Kempton & Kahn, 1999; Löfgren-Mårtenson, 2004; Winges-Yanez, 2014). Despite major policy shifts over the past 30 years regarding the care and support of people with intellectual disabilities, notably the closure of long-stay institutions, and the promise of more socially inclusive models of care and support, challenges still exist. The social model of disability emphasizes the human rights dimension of people with disabilities. However, account needs to be taken of the medical, psychological, social and political factors that impact upon individual's lives. Failure to effectively acknowledge and address health needs adequately is another example of discrimination and the further marginalization of people with intellectual disabilities (Shakespeare, 2012). With deinstitutionalization and a focus on the social model of disability it remains questionable the extent to which adults with intellectual disability have control over their lives and the opportunity to realise their potential, including the expression of their sexuality and all that this encompasses (Shakespeare, 2013).

2. Method

2.1. Research questions

The aim of this review is to synthesize current evidence regarding the experiences and perceptions of adults with intellectual disability regarding the expression of their sexuality and their support needs. Therefore, the questions of this review are:

1. What are the experiences and perceptions of adults with intellectual disabilities regarding their expression of their sexuality?
2. What are the sexuality experiences and needs of adults with intellectual disabilities in relation to education, supports and service utilization?

2.2. Search and selection strategy

A subject Librarian was enlisted to assist with the literature search strategy. The databases used in the search were CINHAL, MEDLINE, PsychINFO and Sociological

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The search terms used were: intellectual disab* OR mental retard* OR learning disab* OR mental handicap OR developmental disab* AND sexuality. The data were accessed from January 2006 to December 2016. An example of the search strategy used in one electronic database is shown in Table 1.

The searches resulted in 230 hits across all the databases. A hand search of reference list identified a further 2 papers. Duplicates and irrelevant articles were removed leaving a total of 141 papers to be considered. The 141 papers were screened by title and abstract against the inclusion criteria and a further 83 papers were excluded leaving 58 papers for full review. Following full review of the 58 papers, a further 35 were excluded on one or more of the following grounds: the study population did not exclusively look at sexuality issues and adults with intellectual disabilities; other reasons were that the sample included children and young people with

Table 1
CINAHL search strategy and results example.

Search code	Query	Results
S1	intellectual disab*	11,956
S2	mental retard*	1592
S3	mental handicap	373
S4	developmental disab*	5738
S5	learning disab*	5740
S6	S1 OR S2 OR S3 OR S4 OR S5	20,896
S7	Sexuality	19,142
S8	S6 AND S7	329
	Limiters were English, peer reviewed, adults	71

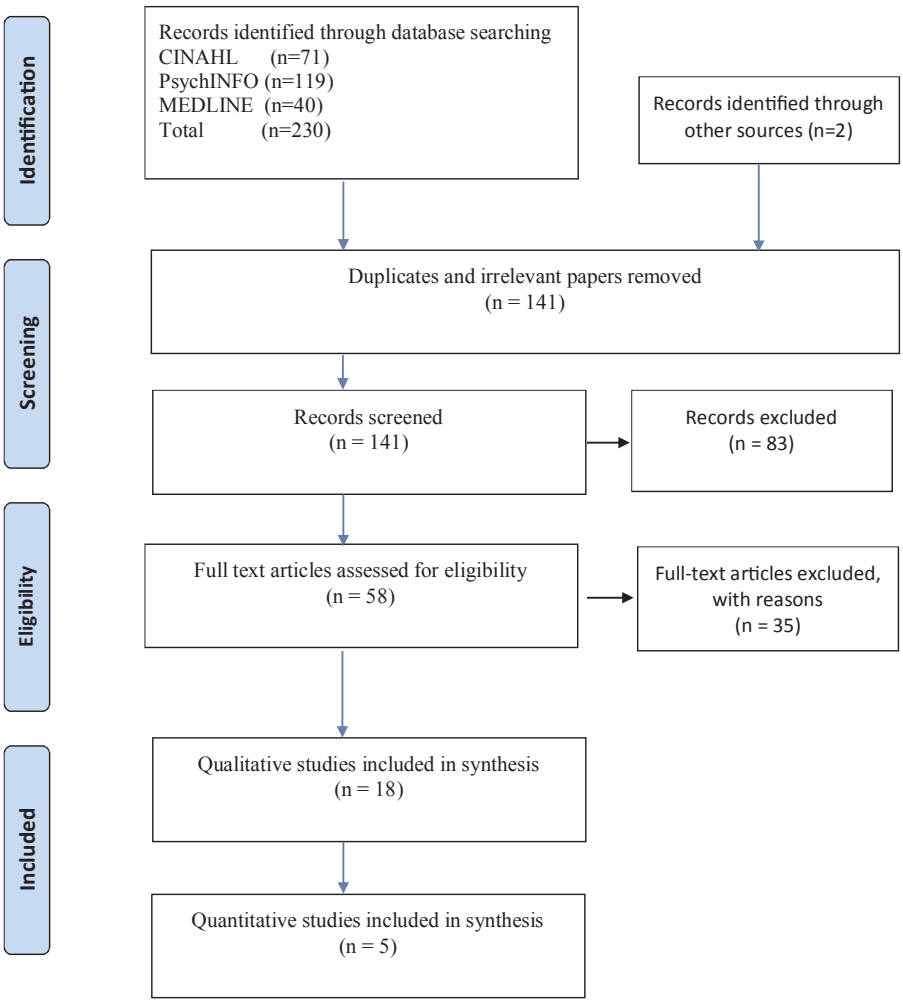

Fig. 1. PRISMA flowchart of systematic review process.

intellectual disabilities, families, professionals and support workers. This resulted in a total of 23 papers for full review and analysis.

Studies were identified that used quantitative or qualitative approaches. The inclusion criteria were adults with intellectual disabilities over 18 years of age and focusing specifically on sexuality experiences. Studies not meeting the inclusion criteria were rejected. The inclusion criteria were limited to academic journals, peer reviewed empirical studies, and written in English. The PRISMA method for reporting the results of the searches was used as detailed in Fig. 1 (Moher et al., 2015).

2.3. Quality assessment

A recognised quality assessment tool, the *Critical Appraisal Skills Programme* (CASP) was used as an evidence-based framework to review the papers (Critical Appraisal Skills Programme, 2013). Specific questions were consistently applied to the 23 selected studies (Table 2). Each question was scored zero, one or two out of a possible score of 20 points. A score of zero was assigned if the paper contained no information, one if there was a moderate amount, and a score of two indicated that the question was fully addressed (Rushbrooke, Murray, & Townsend, 2014). A score of 17 and above, demonstrating the overall quality of the study, was achieved by 7 of the studies (Bedard, Zhang, & Zucker, 2010; Dukes & McGuire, 2009; Eastgate, Van Driel, Lennox, & Scheermeyer, 2011; Rushbrooke et al., 2014; Stoffelen, Kok, Hospers, & Curfs, 2013; Sullivan, Bowden, McKenzie, & Quayle, 2013; Yau, Ng, Lau, Chan, & Chan, 2009). A total of 14 studies scored between 14 and 16, indicating shortcomings in relation to clarity of aims, data collection methods, research relationships considered, and ethics considerations (Arias, Ovejero, & Morentin, 2009; Bane et al., 2012; Bernert, 2011; Bernert & Ogletree, 2013; Box & Shaw, 2014; Fitzgerald & Withers, 2013; Friedman, Arnold, Owen, & Sandman, 2014; Kijak, 2013; Leutar & Mihoković, 2007; O'Callaghan & Murphy, 2007; Siebelink, de Jong, Taal, & Roelvink, 2006; Turner & Crane, 2016; Wheeler, 2007; Yacoub & Hall, 2009). The remaining 2 studies received scores of below 14, due to limited information that impacted on the quality and were related to the aims, ethics, and clarity and detail of findings (Azzopardi-Lane & Callus, 2015; Klepping, 2008). All the studies were deemed suitable for the review as they fulfilled the study inclusion criteria. The issues raised in the appraisal will

Table 2
CASP quality scores.

CASP criteria	Siebelink et al. (2006)	Leutar and Mihoković (2007)	O'Callaghan and Murphy (2007)	Wheeler (2007)	Kleppinng (2008)	Yacoub and Hall (2009)	Dukes and McGuire (2009)	Arias et al. (2009)	Yau et al. (2009)	Bedard et al. (2010)	Bernert (2011)	Eastgate et al. (2011)	Fitzgerald and Withers (2013)	Bane et al. (2012)	Bernert and Ogletree (2013)	Kijak (2013)	Stoffelen et al. (2013)	Sullivan et al. (2013)	Azzopardi-Lane and Callus (2015)	Box and Shaw (2014)	Friedman et al. 2014)	Rushbrooke et al. (2014)	Turner and Crane (2016)
1. Clear statement of aims	1	2	1	1	0	2	2	2	1	2	1	2	2	0	0	2	2	2	0	2	2	2	2
2. Appropriate methodology	2	2	2	2	2	2	2	2	2	2	2	2	2	2	2	2	2	2	2	2	2	2	2
3. Appropriate research design	2	2	2	2	1	2	2	2	2	2	2	2	2	2	2	2	2	2	2	2	2	2	2
4. Appropriate recruitment strategy	2	1	1	1	1	1	2	2	2	2	2	2	0	2	1	1	1	2	2	1	2	2	2
5. Appropriate data collection methods	2	2	2	2	2	2	2	2	2	2	2	2	2	2	2	2	2	2	2	2	2	2	2
6. Research relationships considered	0	1	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
7. Consider ethical issues	0	0	2	0	0	0	2	0	2	2	0	2	2	2	2	2	2	2	1	2	0	2	0
8. Rigorous analysis	2	2	2	2	2	2	2	2	2	2	2	2	2	2	2	2	2	2	2	1	2	2	2
9. Clear findings	2	1	2	2	2	2	2	2	2	2	2	2	2	1	2	1	2	2	1	1	2	2	2
10. Value of the research	2	1	2	2	1	2	1	2	2	2	2	2	1	2	2	1	2	2	1	1	2	2	2
Total scores out of 20	15	14	16	14	11	15	17	16	17	18	15	18	15	15	15	15	17	18	13	14	16	18	16

help guide future research studies which should enhance the overall quality of the available research evidence.

2.4. Characteristics of the selected studies

The 23 studies included in the review that explicitly addressed the study objectives are contained in Table 3. Most of the studies were conducted in the United Kingdom (n = 8). Next was the United States (US) (n = 4), then the Republic of Ireland (n = 2), and Netherlands (n = 2). Each of the following countries had one study respectively: Australia, Canada, China, Croatia, Malta, Poland, and Spain. The studies had sample sizes ranging from single case studies to 376 participants with mild to moderate intellectual disabilities. Most of the studies used qualitative methods (n = 18) including individual interviews, focus groups and case studies. A total of five studies used quantitative methods.

2.5. Data extraction and analysis

A systematic approach, utilizing established methods, was used in the analysis and synthesis of the qualitative and quantitative studies (Mays, Pope, & Popay, 2005). The analysis was conducted in the following ways. The emergent themes, related to the research questions, were identified and coded from the papers, individually and then agreed collectively by the researchers. The identified themes were organized into concepts that allowed for similarities and differences within and between the studies. The themes were then examined by the research team for verification and agreement.

3. Findings

Following the systematic analysis of the studies, five themes were identified: (i) autonomy v's risk of harm, (ii) knowledge and sexuality (iii) self-determination and taking control (iv) relationships and intimacy, and (v) encouragement and supports.

3.1. Autonomy v's risk of harm

A range of concerns were identified that related to the balance and tensions between protection from harm within a relationship, autonomy, and the right to make independent decisions regarding relationships. For some, this may involve being sexually active and may include taking risks. The risk elements appeared to relate to taking emotional risks and vulnerability factors, which, you may argue, are components of any relationship, and contains risks related to the decision to enter into an intimate sexual relationship (Yacoub & Hall, 2009). A recurring theme across studies included in this review related to the tensions between self-determination and protection from potential abuse and exploitation (Friedman et al., 2014; O'Callaghan & Murphy, 2007; Yau et al., 2009). Some people were able to describe positive activities associated with dating while other adults with intellectual disabilities spoke about feeling 'confused' regarding acceptable behaviours, such as intimate touching and what would be considered 'acceptable' (Bernert & Ogletree, 2013; Eastgate et al., 2011; Yau et al., 2009). For others, an expressed concern was about how to set boundaries within a relationship that they felt comfortable with (Sullivan et al., 2013). For some, sexual health concerns related to issues about having both an intellectual and physical disability and how these attributes impact on relationships and the expression of their sexuality, including being intimate and sexually active (Bane et al., 2012). Some individuals spoke of their concerns related to limitations arising from the recognition that their cognitive impairment and the ability to make informed decisions may be impaired to some extent. This may result in placing themselves at risk of exploitation and harm. This realisation, therefore, had significant implications and impacted on decisions related to the person's sexual health and whether to seek an intimate sexual relationship (Klepping, 2008).

3.2. Knowledge and sexuality

A recurring theme for people with intellectual disabilities related to the need for education regarding sexuality and relationships. People with intellectual disabilities spoke about their desire to have an intimate relationship and spoke about the need for support in sustaining it, and assistance in addressing and overcoming difficulties that may be encountered (Leutar & Mihoković, 2007). Linked to this was the identification of education as a means of supporting the development of negotiation skills, necessary within any successful relationship. However, for some their sex education was viewed as incomplete, focusing on protective measures rather than enhancing their sexual knowledge and relationships (Yau et al., 2009). Additionally, having access to opportunities to talk about their sexuality and sexual relationships was desired by people with intellectual disabilities, but in a way that was safe and personal (Kijak, 2013). For some adults with intellectual disabilities, their sexual knowledge was lacking with some holding stereotypical views towards sex and marriage (Yau et al., 2009). Knowledge regarding developing and sustaining relationships was desired by people with intellectual disabilities, underpinned by the development of their knowledge and skills in enhanced decision making to enable choices regarding their sexuality and the relationships they enter into (Dukes & McGuire, 2009; Siebelink et al., 2006).

3.3. Relationships and intimacy

Both men and women with intellectual disabilities referred to their wish and desire for relationships and for some, this may be sexual; for others, there was a desire for intimacy and friendship (Siebelink et al., 2006). It became apparent, that a presumption exists that people with intellectual disabilities are somehow 'asexual,' not sexually active, and in need of 'protection' (Arias et al.,

2009). Conflicting views were apparent between the desire for self-determination, including having choices and making decisions regarding the expression of sexuality and establish relationships, and the concerns of families and carers related to fears of exploitation and sexual abuse and their need to exercise more control (Eastgate et al., 2011). For people with intellectual disabilities currently in a relationship, issues emerged that related to knowledge regarding the age of consent, marriage and the protection afforded through laws (O'Callaghan & Murphy, 2007). People with intellectual disabilities highlighted a lack of privacy as a contributory factor to inhibiting their opportunities to establish relationships and express their sexuality (Bernert, 2011). From the perspective of care providers, organisational policies and protocols were seen as a contributory factor restricting their right to express their sexuality and establish relationships that for some may be of a sexual nature (Bane et al., 2012). Both men and women with intellectual disabilities highlighted that their views, opinions, needs and the right to self-determination were, in some cases, not recognised and even ignored (Bernert, 2011; Wheeler, 2007).

3.4. Self-determination and taking control

It is apparent that some men and women with intellectual disabilities want to have, and be able to talk about, loving relationships; they seek passion, romance and intimacy (Wheeler, 2007). For some, this may involve being sexually active. People want influence over forming and maintaining intimate personal relationships. They want to be more in charge of this part of their lives, rather than being controlled by others (Arias et al., 2009). The evidence supported the recognition of the need for support to enabled informed choices and for individual decisions to be made (Bedard et al., 2010). The role of education programmes and independent advocacy was seen as important to facilitate decision making and self-determination, thereby reducing paternalistic protectionism and the possible disenfranchising dependency on families and care workers (Bane et al., 2012). Addressing these needs would enable people with intellectual disabilities to build and grow their personal strengths and attributes, develop emotional well-being and support the full expression of the person's sexuality (Arias et al., 2009).

For some people with intellectual disabilities, relationships extended beyond the biomedical interpretation. Establishing and developing loving and intimate relationships was seen as part of the development of individual sexual identity and the expression of sexuality (Bernert, 2011; Turner & Crane, 2016). Participants identified psychosocial considerations and potential barriers to the expression of their sexuality. These included practical obstacles such as access to transport and the ability to self-travel. For others, the barriers were attitudinal and related to low personal self-worth and value, and the right to be 'sexual' and experience intimate relationships (Bane et al., 2012). For some, being sexually active was viewed as 'dirty' and something to be avoided (Fitzgerald & Withers, 2013). Studies highlighted the issue of differences in gender identity and the need for the recognition and acknowledgement of diversity within the intellectual disability communities (Bedard et al., 2010; Stoffelen et al., 2013).

3.5. Encouragement and supports

Central to the expression of their sexuality, both men and women with intellectual disabilities want to know that they are being listened to and their wishes and needs are regarded and respected (Bane et al., 2012; Fitzgerald & Withers, 2013; Wheeler, 2007). For some, they can feel embarrassed about discussing issues related to their sexuality; a situation that can be compounded by a lack of recognition by families and support staff that people with intellectual disabilities are sexual beings; some are and wish to be sexually active (Bernert & Ogletree, 2013; Yau et al., 2009). The situation is further exacerbated by a lack of attention on the behalf of support staff about the relationships that they have or may desire to have. Opportunities to discuss their sexuality and intimate relationships is not usually on the agenda and is one that appears to be largely ignored (Box & Shaw, 2014; Friedman et al., 2014; Rushbrooke et al., 2014; Yau et al., 2009).

Furthermore, some women with intellectual disabilities have highlighted the often-limited sexual experiences, and for those who had, they held negative perceptions about sex. They did not perceive it as an option that they could pursue. The most commonly cited activity for men with intellectual disabilities, was autoerotic sexual behaviour, by way of masturbation, watching adult and prostitution, rather than partner intimacy (Kijak, 2013; Siebelink et al., 2006). For some women with intellectual disabilities, the situation was compounded by a lack of self-confidence in their physical appearance and the ability to express their sexuality and to seek and maintain an intimate relationship (Fitzgerald & Withers, 2013). An important issue that was identified as impacting on sexual development related to the level of intellectual impairment; the more severe the level of disability the less developed was the ability to express one's sexuality (Bane et al., 2012). From the perspective of people with intellectual disabilities who identify lesbian, gay, bisexual or transgender (LGBT), opportunities to express their sexuality was sporadic and the necessary available supports were limited. There remains a presumption that people with intellectual disabilities are heterosexual, with limited recognition of the possibility that some may be non-heterosexual and have experiences and support needs (Stoffelen et al., 2013).

From the perspective of people with intellectual disabilities, there is a desire for the development of a person-centred approach from their families, professionals and support workers that enables individuals to explore and express their sexuality (Bane et al., 2012). To enable this, people with intellectual disabilities highlighted the need to have more social experiences that would provide opportunities to meet new people, with the potential to establish friendships or intimate relationships. As part of the experience of expressing their sexuality and seeking, establishing and maintaining an intimate relationship, people with intellectual disabilities expressed the need for access to support services such as advocacy, counselling and talking therapies (Azzopardi-Lane & Callus, 2015; Friedman et al., 2014).

4. Discussion

This review has identified a range of key issues that exist in relation to the experiences and needs of adults with intellectual disabilities regarding their sexuality. The findings from this review indicate areas requiring attention in terms of policy, education, individual supports and future research developments. A useful way of conceptualizing the issues is through *Bronfenbrenner's Ecological Model* as a framework to present the discussion of areas requiring development (Bronfenbrenner, 1979). The model offers a structure to support a strengths-based approach to understanding the needs of people with intellectual disabilities and the expression of their sexuality, and how they may be effectively addressed. The Ecological Model is multi-systemic and contains elements that can help practitioners better understand the experiences and health needs of specific populations (Institute of Medicine, 2011). The model sets out different levels that interface with each other and interact to shape the environment including macro, meso and micro systems. Each of the systems relates to the environments and interactions throughout the lifespan of the individual that may influence human behaviour (Bronfenbrenner, 1979). Arising from this, is the need for improvements in health and social care services necessary to address social, cultural and political determinants that impact upon and contribute to social exclusion and health inequalities.

4.1. Macro system

The macro system is the overarching template that sets out the societal norms and cultural attitudes that impact on and influence the life of the individual. This review has highlighted issues in relation to the important and necessary developments that have occurred for adults with intellectual disabilities from institution-based models to social inclusion and community orientated approaches to care and service provision (Department of Health, 2001; Scottish Executive, 2000). While these developments are necessary and welcome, many people with intellectual disabilities continue to experience prejudice, discrimination, victimisation and a lack of control and decision making within their daily lives (Fisher, Baird, Currey, & Hodapp, 2016; Overmars-Marx, Thomése, Verdonschot, & Meininger, 2014; Prime Minister's Strategy Unit, 2005; Simplican, Leader, Kosciulek, & Leahy, 2015;). This is particularly the case in relation to the expression of their sexuality, which, for the majority in the non-disabled population, is viewed as a fundamental human right and one that it taken for granted (Hall, 2010; McCann, Lee, & Brown, 2016). There are therefore a range of actions that are necessary from policy makers, implementers and service providers across education, health, social care and non-governmental organisations. Providers of services need to be aware of, and actively address, issues and concerns in collaboration with adults with intellectual disabilities (Kline & Preston-Shoot, 2012).

From a legislation and policy perspective, two themes from the findings, *autonomy vs risk of harm* and *self-determination and taking control*, are particularly relevant with action required on several fronts. Some relevant legislation has been implemented that provides protection from discrimination and harm and affords access to assessment, treatment, care and support. However, there is still a need to ensure that legislation is evenly applied in a way that is enabling of adults with intellectual disabilities to express their sexuality and not to place needless and unnecessary limits that prevents such expression. This is important as some adults with intellectual disabilities may have limited knowledge and understanding of how legislation can afford them protection and of their own responsibilities (O'Callaghan & Murphy, 2007). From the results of the review, theme (ii) − *knowledge and sexuality*, highlights that adults with intellectual disabilities want access to education regarding the expression of their sexuality, as well as advocacy and supports about their rights and responsibilities, that also includes protection from exploitation and abuse (Dukes & McGuire, 2009; Schaafsma, Kok, Stoffelen, & Curfs, 2015). However, there are possible tensions and challenges for all concerned in providing support that is least restrictive and more enabling, while responding to and preventing abuse, exploitation and harm (Byrne, 2017; Healy, McGuire, Evans, & Carley, 2009; Murphy & O'Callaghan, 2004). Also, there remains possible conflicts between the rights, autonomy and aspirations of adults with intellectual disabilities regarding control over their sexual expression. However, concerns still exist regarding vulnerability, exploitation and abuse from the perspective of families and carers (Rushbrooke et al., 2014).

From this systematic review and the results from theme (iii), *self-determination and taking control*, it is evident that adults with intellectual disabilities have and want intimate relationships and for some, this involves being sexually active. Existing policies, specifically developed to improve the lives of people with intellectual disabilities, need to ensure they adopt a rights-based approach to the expression of sexuality. Furthermore, the rights of the population to independence and to make decisions that enables to them to take control of their lives, needs to be realised (Department of Health, 2001; Scottish Government, 2013). From a policy perspective, action is required on two broad fronts. Jurisdictions that have developed intellectual disability specific policies need to ensure that they take account of and reflect the aspirations of people with intellectual disabilities in relation to the expression of their sexuality. There is a need to fully implement and evaluate such policies and their impact upon day-to-day practice thereby bringing about the changes required by people with intellectual disabilities (Overmars-Marx et al., 2014). Furthermore, jurisdictions who have yet to develop intellectual disability specific policies need to do so. These policies should incorporate a clear focus on the sexuality aspirations of people with intellectual disabilities and facilitate their implementation within routine practice.

More specifically, sexual health policies need to take account of the distinct and unique needs of adults with intellectual disabilities and tailor services accordingly. Necessary adjustments need to be made to services to enable equality of access and additional support to ensure that the needs of the individual are effectively assessed and met (Heslop, Hoghton, & Marriott, 2014; Turner & Robinson, 2011). To promote human rights and quality of life, community-based residential and day care service providers need to ensure that their local policies are set within this context and take account of, and clearly reflect, the aspirations and needs of adults with intellectual disabilities, including the expression of all aspects of their sexuality (McCann et al., 2016; Verdugo, Navas, Gómez, & Schalock, 2012).

From the perspective of adults with intellectual disabilities, the results from theme one – autonomy and risk of harm and theme three – self-determination and taking control, highlights that care organisations may have unnecessary restrictions in place that inhibit rather that facilitate the expression of their sexuality and intimate relationships, suggesting that this continues to be a 'grey area' of continuing ambiguity (Rushbrooke et al., 2014). In some areas, specialist intellectual disability services have been developed that include a range of professionals such as clinical psychologists, social workers, nurses and psychiatrists, to work directly with adults with intellectual disabilities and care providers. They may provide access to capacity assessments, therapy, advice and support regarding sexuality and relationship issues for those with more complex support needs (Slevin, Truesdale-Kennedy, McConkey, Barr, & Taggart, 2008). Models of co-production and supported decision making offer a solution that can be used to fully involve adults with intellectual disabilities to inform and shape local policy that reflects their rights and aspirations and organizational responsibilities to protect and safeguard those most at risk of harm (Palumbo, 2016; Voorberg, Bekkers, & Tummers, 2015).

4.2. Micro system

The micro system sets out the direct contacts and personal relationships of adults with intellectual disabilities and includes their friends, family, peers, romantic relationships and support workers. Support networks are central to the well-being, ongoing development and social inclusion of all adults with intellectual disabilities who may require access to additional guidance and supports.

From the analysis of the studies forming this review, theme (iv), *relationships and intimacy,* indicates that adults with intellectual disabilities desire and may already experience intimate relationships; some may be sexual. For many, there is a need for additional support, time and resources to assist with understanding and exploring their sexuality (Box & Shaw, 2014). Findings set out in theme (v), *encouragement and supports* highlights the limited opportunities to meet people, with whom they might wish to consider establishing an intimate relationship, due to a range of factors. These may include self-confidence issues, concerns regarding appearance, and awareness of their cognitive limitations (Arias et al., 2009; Turner & Crane, 2016). Women with intellectual disabilities may need access to help and support to enable them to recognise and appreciate their sexuality. For others, there is a need to address issues from their past, including negative self-perceptions and experiences, feelings related to 'missed' opportunities and for some, access to therapy to address experiences of sexual abuse (Hellenbach, Brown, Karatzias, & Robinson, 2015; McCarthy, 2014; Winges-Yanez, 2014). For men with intellectual disabilities, they too seek intimate relationships, and yet many experiences obstacles, with a desire to develop what they consider to be a 'normal' sexual identity (Wilkinson, Theodore, & Raczka, 2015). The representation of men with intellectual disabilities within the established body of literature often focuses on them as victims of sexual abuse, vulnerable and open to exploitation (Cambridge, Beadle-Brown, Milne, Mansell, & Whelton, 2011). Another perspective emerging from the body of evidence, presents offending behaviours, some of which are sexual in nature and the available treatment options and interventions (Cohen & Harvey, 2016; Fisher et al., 2016). For some men, there are missed opportunities to fully explore and realise their sexuality and sexual potential and to experience intimate relationships (Wilkinson et al., 2015; Wilson & Plumber, 2014).

There is a growing and evolving evidence base regarding people with intellectual disabilities who identify as LGBT and the challenges that many experience in expression their sexuality (McCann et al., 2016). Three themes capture the complexity of individual circumstances: (i), *autonomy vs risk of harm* (ii), *knowledge and sexuality* and (iii), *self-determination and taking control*, evidencing the concerns regarding vulnerability and exploitation, limited sexual health knowledge, and same sex relationship opportunities. These issues may be further compounded by limited recognition of a possible LGBT identity by other people with intellectual disabilities, their families and carers. Prejudice and assumptions regarding heteronormativity prevail (Elderton, Clarke, Jones, & Stacey, 2014; Löfgren-Mårtenson, 2009, 2012). From the perspective of women with intellectual disabilities, there is limited recognition and attention paid to those who identify as lesbian (McCann et al., 2016). Access to education, LGBT networks of social support and opportunities to meet other LGBT people, are recurring issues that need to be addressed. This is necessary to minimise the potential for social isolation, mental ill-health and to develop resilience and build on positive strengths and capabilities (Conder, Mirfin-Veitch, & Gates, 2015; Elderton et al., 2014; McClelland et al., 2012; Stoffelen et al., 2013; Wigham & Emerson, 2015).

Irrespective of sexuality, adults with intellectual disabilities want friendships, social support and social networks as a mean to form new relationships, with the potential, if desired, for intimacy (Box & Shaw, 2014; Fitzgerald & Withers, 2013; Yacoub & Hall, 2009). Theme (v) of this review, *encouragement and supports*, indicates that there are a range of factors that need to be addressed to support adults with intellectual disabilities to develop friendships and build and maintain social networks. These include: access to reliable transport, the proximity to friends and family, the availability and facilitation to access social networks, leadership from professionals, integrative activities, and dealing with potential dilemmas (Craig & Bigby, 2015; van Asselt-Goverts, Embregts, & Hendriks, 2013). Failure to address these issues with adults with intellectual disabilities, further restricts options to participate fully in their community, expand social networks and events, and meet up with friends. This contributes to ongoing wider social exclusion and isolation (Wiesel & Bigby, 2014).

4.3. Meso system

The meso system focuses on the relationships and interactions between the adult with intellectual disabilities and the micro system. An example of this is the relationships between the adult with intellectual disabilities, their support worker and *vice versa*.

Recurring themes arising from this review: (ii), *knowledge and sexuality* and (iv) *relationships and intimacy* demonstrates the need for access to education about relationships and a desire to increase knowledge regarding the expression of their sexuality and extends to establishing and maintaining intimate relationships (Arias et al., 2009; Box & Shaw, 2014; Dukes & McGuire, 2009; Eastgate et al., 2011; Friedman et al., 2014; Leutar & Mihoković, 2007). Networks of social support and access to social activities are important for

positive health and well-being, in the creation of opportunities to develop new friendships and possible relationships (Simplican et al., 2015). They are an important issue for adults with intellectual disabilities and one that requires development, as many feel lonely and socially isolated (Gilmore & Cuskelly, 2014). Navigating relationships and resolving conflicts and dilemmas within friendships and relationships are areas where adults with intellectual disabilities want help and support (Box & Shaw, 2014). There is an important opportunity for professionals and support workers to be sensitive to, and create opportunities for the adults they work with, to discuss issues and concerns regarding their friendships and relationships, thereby helping to develop and sustain them.

Two themes from the findings, (i) *autonomy vs risk of harm* and (ii), *knowledge and sexuality* details the occurrence of significant life events such as bullying, exploitation, rape and sexual abuse for some adults with intellectual disabilities. Yet, despite this, access to evidence-based psychological therapies and support is limited (Eastgate et al., 2011; Hulbert-Williams et al., 2014; Osugo & Cooper, 2016; Stoffelen et al., 2013). Developing positive health and improving health-seeking behaviours is important for many adults with intellectual disabilities, given the evidence of their poor health and barriers to accessing healthcare (Ali et al., 2013; Cooper et al., 2015; Krahn & Fox, 2014). Mental ill-health is common in people with intellectual disabilities by way of depression, anxiety disorder, phobias and psychotic illness. This may be due to biological and genetic factors and life events, being female, the type of support provided, and being of a lower level of ability (Cooper, Smiley, Morrison, Williamson, & Allan, 2007). Therefore, improving access to counselling and talking therapies is necessary to ensure that adults with intellectual disabilities have access to the services they require to promote autonomy, decision making and self-determination (Bane et al., 2012).

4.4. Future research directions

This review highlights the ongoing need for a specific-research focus on sexuality and adults with intellectual disabilities to understand their needs, mechanisms of support that work, interventions and service responses. It is encouraging that some studies that comprised this review had adults with intellectual disabilities as researchers and collaborators and there is scope to develop this further. There is an absence of policy evaluation, education evaluation, sexuality and quality of life studies, epidemiology and intervention studies; these are areas requiring further research. There was a limited focus on the sexuality of adults with intellectual disabilities who identify as LGBT, and an even more limited focus on lesbians and transgender people with intellectual disabilities; this is a shortcoming that needs further investigation. There were no multi-centre national or international studies and there is scope for larger projects across different geographical areas and countries. For adults with intellectual disabilities, education and training and access to additional support to explore and discuss their sexuality concerns were important recurring themes; there is a need to research their effectiveness and outcomes. Given the evidence of health inequalities and high health needs of people with intellectual disabilities and concerns related to abuse and mental illness, there is an opportunity to research the effectiveness of treatments and psychological interventions.

4.5. Strengths and limitations of the review

There is an increasing and growing body of research evidence of the experiences and needs of adults with intellectual disabilities regarding their sexuality. This review has uncovered and identified important concerns that can guide and inform policy, education, practice and the support needs of adults with intellectual disabilities. This is necessary if the drive towards social inclusion and responsive, individualized care and support, is to be a reality. In terms of the available evidence, limitations exist due to the robustness of the study designs; an issue that is a potential challenge when undertaking research with this population. The authors have sought to be rigorous in the review process and acknowledge the potential for subjectivity. To address this, a recognized framework was used and applied consistently throughout.

5. Conclusion

Enjoyment and celebration of sexuality is recognized as a core component of human experience (World Health Organization, 2015). This systematic review exclusively highlights the voices of adults with intellectual disabilities in relation to the expression of their sexuality and identifies key priorities for their future support needs. It has become clear from this review that adults with intellectual disabilities want friendships, meaningful relationships and, for some, intimacy. It is irrefutable that some adults with intellectual disabilities are vulnerable and open to abuse and exploitation. Therefore, it is essential that there are appropriate policies and frameworks in place that afford adults with intellectual disabilities protection from unnecessary risk and harm. For this to become a reality, individuals seek access to education that enables the development of their knowledge and decision making capacity regarding sexuality opportunities. Failure to address these complex and often interrelated issues may result in adults with intellectual disabilities continuing to be viewed paternalistically. Families, professionals and support workers involved in providing care and support have important roles to play in working collaboratively to establish individual hopes and aspirations to help people reach their fulfilment as sexual beings and express their sexuality in whatever form that may take.

Conflict of interest

The authors declared no conflict of interest.

Table 3
Papers included in the review.

	Study Citation and Country	Aims	Sample	Data collection method	Key Findings	CASP scores out of 20
1.	Siebelink et al. (2006) Netherlands	To investigate sexual knowledge, attitudes, experiences and needs of people with intellectual disabilities	76 Adults (male n = 47) (female n = 29)	Quantitative methods: Semi structured interviews. 28 items on sexual knowledge, sexual attitudes, sexual and relational experience and needs	Sexuality and romantic relationships important. Males reported more sexual needs.	15
2.	Leutar and Mihoković (2007) Croatia	To investigate the sexual knowledge of adults with intellectual disabilities	Twenty-four adults with intellectual disabilities (male n = 14) female n = 10)	Qualitative methods: Questionnaire and interviews	Poor knowledge about sexuality and sexual health issues and protection against sexually transmitted infections. A good level of knowledge about appropriate and inappropriate sexual behaviours shown.	14
3.	O'Callaghan and Murphy (2007) United Kingdom	To investigate the sexual knowledge of adults with intellectual disabilities in relation to the law	Mixed sample of sixty adults with and without intellectual disabilities (males n = 30 with ID) and (females n = 30 with ID) and 60 without intellectual disabilities	Quantitative methods: All participants completed a 30-item questionnaire developed by the researchers and the Social Network Map, sexual knowledge using the Sex-KID and understanding of abuse with questions taken from 'Sex and the 3Rs'. People with intellectual disabilities were tested using the Weschler Abbreviated Scale of Intelligence (WASI) to assess IQ.	Differences were identified between the two groups with the intellectually disabled having a poor understanding of laws related to sexuality, such as age of consent and having a sexual relationship, getting married and protection available under law.	16
4.	Wheeler (2007) United Kingdom	To investigate how men with intellectual disabilities in Wales view and experience their sexuality	Adult men with intellectual disabilities	Qualitative methods: Two focus groups and 12 semi-structured interviews	Participants viewed themselves as sexual beings. Limited opportunities to express their sexuality which was controlled by others. Men with intellectual disabilities recognise their differences in relation to their sexuality rather than the similarities with the non-disabled.	14
5.	Klepping (2008) United Kingdom	To explore the views and experiences of a married couple with intellectual disabilities regarding sexuality and dementia	A married couple, one with a diagnosis of dementia and intellectual disabilities	Qualitative methods: A case study interview design	A holistic approach is required towards the expression of sexuality and people with intellectual disabilities and a diagnosis of dementia that takes account of their emotional, physical and social support needs and individual circumstances and personal values.	11
6.	Yacoub and Hall (2009) United Kingdom	To explore the sexual lives and behaviours of men with mild intellectual disabilities living in the community and residential settings and identify unmet needs.	Adults with mild intellectual disabilities; 8 living in their own tenancy and 2 in residential care. (males n = 10)	Qualitative methods: A qualitative, semi-structured interview schedule was developed that was informed by the SexKen-ID scale with themes developed that focused on friendships, sex education, sexual interaction, contraception, STIs, sexual orientation and perceptions of sexual lives.	Participants could express their sexuality and sexual identity and found services to be supportive. Sexual vulnerability was evident with some participants feeling coerced into sex. Concerns were identified in relation to risks of sex in public places. Sexual knowledge did not equate to safe sexual practices.	15
7.	Dukes and McGuire (2009) Republic of Ireland	To apply an educational intervention regarding sexual knowledge and adults with intellectual disabilities to determine if capacity in sexuality-related decision making can be improved.	Four adults with moderate intellectual disabilities (male n = 2) (female n = 2)	Quantitative methods: An exploratory, single subject study design involving the delivery of an educational intervention with multiple base-line measures using: *The Inappropriate Sexual Behaviour Scale, SCEA – K-Scale and SCEA – S – Scale*	Participant improvements in knowledge resulted in improvements in their decision-making capacity, with 3 follow-up at 6 months demonstrating some decision-making maintenance.	17

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Table 3 (*continued*)

	Study Citation and Country	Aims	Sample	Data collection method	Key Findings	CASP scores out of 20
8.	Arias et al. (2009) Spain	To develop a theoretical model of love in people with intellectual disabilities	Three hundred and seventy-six adults with mild intellectual disabilities (n = 376)	Quantitative methods: The development and testing of the *Specific Scale to Assess Love in People with Intellectual Disabilities*	People with intellectual disabilities seek self-determination regarding their relationships; excitement, intimacy and romanticism in keeping with the non-intellectually disabled and self-determination and relationships free from family interference.	15
9.	Yau et al. (2009) China	To explore sexuality and sexual concerns of people with intellectual disabilities	Twelve adults with intellectual disabilities (males n = 3) female (n = 9)	Qualitative methods: Semi-structured interviews	5 themes: dating and marriage, sexual attitudes, sexual behaviours, knowledge, familial attitudes and normalization.	17
10.	Bedard et al. (2010) Canada	To investigate gender identities and sexual orientations of people with intellectual disabilities,	Thirty-two adults with intellectual disabilities (male n = 16) (female n = 16)	Quantitative methods: 5 questionnaires: 10-item demographic questionnaire; Erotic Response and Orientation Scale; Sexual History Questionnaire; Recalled Childhood Gender Identity/Gender Role Questionnaire; Gender Identity Questionnaire for Adults.	Most participants defined themselves as heterosexual, two as bisexual and one as homosexual. Four participants had Gender Identity Dysphoria. 84% of participants reported abuse. Families and professionals need to be aware that people with intellectual disabilities present with different gender identities.	18
11.	Bernert (2011) United States	To explore how sexuality influences and is experienced by women with intellectual disabilities within their daily lives and to identify supports required.	Fourteen adult women with intellectual disabilities (females n = 14)	Qualitative methods: Multiple one: one interviews (n = 48) and direct observations (n = 28) and focus groups (n = 2).	Most of the participants lived within services for people with intellectually disabled yet did not have disability identity. Most expressed an adult identity that resulted in their expectations of sexual autonomy; 9 participants had experience of dating, had dated or married men with intellectual disabilities or some other disability. Participants experienced limits to the expression of their sexuality limitations due to restrictive policies aimed at protection.	15
12.	Eastgate et al. (2011) Australia	To explore how women with intellectual disability understand sex, relationships and sexual abuse.	Nine adult women with intellectual disabilities (females n = 9)	Qualitative methods: Semi-structured one: one interviews	Participants gained their sexual knowledge from a range of sources; expectations from sexual relationships vary and need to be negotiated. Some participants were confused regarding declining unwanted sexual contact, including with partners. Self-protection strategies need to be developed to minimise risk of sexual abuse and the consequences of it.	18

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Table 3 (*continued*)

	Study Citation and Country	Aims	Sample	Data collection method	Key Findings	CASP scores out of 20
13.	Bane et al. (2012) Republic of Ireland	To explore the views and perspectives of people with intellectual disabilities regarding on relationships and supports.	Ninety-seven adults with intellectual disabilities (males n = 45) (females n = 52)	Qualitative methods: Focus Groups	Participants want a relationship and can feel embarrassed talking about their needs. Many want help from family and support workers with their relationships and how to keep them. Transport to visit friends is a barrier. Having a home of their own is important to invite friends to, including when in a relationship. People with intellectual disabilities want to lobby for legislative change to ensure their right to a relationship are protected.	15
14.	Bernert and Ogletree (2013) United States	To explore how women with intellectual disabilities perceive their sexuality and how sexuality functions in their lives.	Adult women with intellectual disabilities (females n = 14)	Qualitative methods: Semi-structured one: one interviews	Many of the participants had limited sexual experiences with most abstaining; all that had a sexual relationship were heterosexual. Regarding being sexually active, participants identified having protected sex, marital and monogamous sex for the purpose of childbearing and having feelings for a sexual partner. Many of the participants had negative perceptions of sex and attributed this to fear of the sexual act, potential negative consequences and possible lack of pleasure.	15
15.	Fitzgerald and Withers (2013) United Kingdom	To explore how women with intellectual disabilities conceptualise their sexuality and develop a sexual identity.	Ten adult women with intellectual disabilities (females n = 10)	Qualitative methods: Semi-structured interviews	Many participants did not view themselves as sexual beings. They considered themselves to be of little value and had no sense of self-identity as women. Some held negative beliefs that sex was 'dirty' and an inappropriate activity. Many were of the view that other people stopped them from being sexually active.	15
16.	Kijak (2013) Poland	To identify the sexual development of people with intellectual disabilities and their knowledge of sexual life and sexual activities.	Adults with mild intellectual disabilities from (n = 133)	Qualitative methods: 1:1 interviews using a structured questionnaire	The sexual development of participants was delayed on average by 3 years. The level of intellectual disability effects sexual development. Some young people with intellectual disabilities are engaged in sexual activity. Participants participated in autoerotic behaviour rather than partner relationships.	15
17.	Stoffelen et al. (2013) Netherlands	To identify the lived experiences of people with an intellectual disability who are homosexual in the Netherlands?	Twenty-one adults with intellectual disabilities (males n = 19) (female n = 2)	Qualitative methods: Semi-structured interviews	Participants reported both positive and negative experiences regarding their sexuality and gay and lesbian identity. Almost half of the participants reported sexual abuse including partner violence. There is limited support for people with intellectual disabilities who are homosexual.	17

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Table 3 (*continued*)

	Study Citation and Country	Aims	Sample	Data collection method	Key Findings	CASP scores out of 20
18.	Sullivan et al. (2013) United Kingdom	To explore the experiences and perceptions of close and sexual relationships of people with an intellectual disability.	Ten adults with intellectual disabilities (males n = 6) (females n = 4)	Qualitative methods: Semi-structured interviews	Touching other people when in a relationship was reported by participants as part of the expression of their sexuality. Participants reported that touching within relationships was wrong and it was not safe to talk about it and it was safe to suggest touching. Participants reported having limited freedom and 'fun' and that being touched is an important part of relationships.	18
19.	Box and Shaw (2014) United Kingdom	To explore the experiences of people with intellectual disabilities regarding their sexuality and relationships and of attending a sexuality and relationship group.	Five adults with intellectual disabilities attending a sexuality and relationship group. (male n = 3) (female n = 2)	Qualitative methods: Semi-structured one: one interviews following completion of the sexuality and relationship group.	Participants enjoyed attending the group over the 10-week duration and felt that they had increased their knowledge about sexuality and relationships and benefited from attending with other people with intellectual disabilities of both genders.	14
20.	Friedman et al. (2014) United States	To explore how people with intellectual disabilities define and experience sexuality as a self-advocate.	Thirty-five male and female adults with intellectual disabilities (n = 35)	Qualitative methods: Nominal Group Technique (NGT)	People with intellectual disabilities want access to information and sexual health services and access to counselling services. Participants wanted the removal of systemic barriers that limit and inhibit the expression of their sexuality; there is a need to educate families and people involved in their support.	16
21.	Rushbrooke et al. (2014) United Kingdom	To explore the experiences of people with intellectual disabilities and intimate relationships	Nine adults with intellectual disabilities (males = 4) (females = 5)	Qualitative methods: One: one interviews	People with intellectual disabilities want intimate relationships and opportunities to express their sexuality. People with intellectual disabilities want control over their relationships.	18
22.	Azzopardi-Lane and Callus (2015) Malta	To identify the perceptions of sexuality of the people with intellectual disability and how they are influenced by social and cultural norms.	Forty adults male and female participants with intellectual disabilities attending a self-advocacy group. (n = 40)	Qualitative methods: Focus Group interviews	Participants were aware of their sexuality it is an issue of interest to them and how it was viewed by others. Findings highlight issues related to lack of privacy, limited finances and a reliance on others for support. Some participants reported their sexual expression was limited and controlled by parents and carers regarding developing relationships.	13
23.	Turner and Crane (2016) United States	To explore how adults with mild intellectual disabilities live out their social-sexual lives.	Five adults with intellectual disabilities (males = 3) (females = 2)	Qualitative methods: Direct observations and semi-structured interviews	People with intellectual disabilities seek intimacy and human connectedness and opportunities for sexual experiences and the development of their sexual identity; some feel a sense of shame. Research to date has often focused in reproduction and sexual abuse and safety.	16

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The views and experiences of families and direct care support workers regarding the expression of sexuality by adults with intellectual disabilities: A narrative review of the international research evidence

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ABSTRACT

Background: There is a growing and evolving research evidence base regarding sexuality issues and adults with intellectual disabilities. However, the experiences and views of families and direct care support workers and their support and development needs in the topic area are unclear.

Aims: The aim of this narrative review was to explore the views and experiences of families and direct care support workers in relation to the expression of sexuality by adults with intellectual disabilities and to identify their distinct support and development needs.

Methods and procedures: A comprehensive search of relevant databases from May 1998 to June 2018 was undertaken. Included studies had to address specific criteria: peer reviewed papers, the use of appropriate research methods, and focus exclusively on the individual views and opinions of families and direct care support workers. The search of relevant databases yielded 313 hits. Following the application of explicit inclusion and exclusion criteria, 11 papers were deemed suitable for the review. The PRISMA checklist was utlised in the process. Quality was assessed using a recognized framework.

Outcomes and results: The data were analysed and key findings highlighted issues for families and direct care support workers including: attitudes and beliefs; fear of abuse, exploitation and harm; new technologies; supporting developments in practice; and education and training programmes.

Conclusions and Implications: Families and direct care support workers have specific support and education needs. Future healthcare initiatives need to be developed that are fully responsive to the identified concerns and requirements of families and direct care support workers.

What this paper adds?

Adults with intellectual disabilities (ID) may require care and support from families and carers to enable them to lead independent lives and make choices and decisions. This review highlights issues and concerns from the available research among families and direct care support workers in enabling adults with ID to express their sexuality. The discussion presents areas relevant to policy, education and future research priorities.

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1. Introduction

The aim of this paper is to present the views and experiences of families and direct care workers regarding the expression of sexuality by people with ID. For the purpose of this review, a direct care support worker refers to a paid member of staff who works on a day-to-day basis with the person with ID providing direct care and support.

There has been a drive towards a more socially inclusive healthcare system that is receptive to all aspects of the needs of the individual, achieved through the development and delivery of responsive, person-centred healthcare services (World Health Organisation, 2015). A fundamental component in human development is the expression of sexuality (World Health Organisation, 2013). Whilst there is more recognition and attention being paid to sexuality across healthcare settings, the impact of appropriate supports and interventions remains elusive (World Health Organisation, 2010). People with ID want friendships, relationships and intimacy (Rushbrooke, Murray, & Townsend, 2014; McCann, Lee, & Brown, 2016; Turner & Crane, 2016; Bates, Terry, & Popple, 2017; Brown & McCann, 2018). A recent systematic review that highlighted the views, experiences and aspirations of people with ID regarding their sexuality set their hopes and aspirations and a range challenges and areas of potential conflict experienced by people involved in their support and care (Brown & McCann, 2018). Despite their desires, it is particularly evident that many face additional barriers and challenges to achieving this and fully expressing their sexuality, with families and carers unsure how best to provide support (McCann et al., 2016; Rushbrooke, Murray, & Townsend, 2014).

This is regardless of the social model of disability that highlights the importance of equality, human rights and the inclusion of people with disabilities as equal citizens (Simplican, Leader, Kosciulek, & Leahy, 2015). This requires that care providers and caregivers adopt more empowering, person-centred and inclusive approaches to the services and supports provided to people with ID (van der Meer, Nieboer, Finkenflügel, & Cramm, 2018). These, factors, along with changes in social policy, such as deinstitutionalization strategies, has presented opportunities to address issues such as the expression of sexuality. Increasingly, with the locus of care being situated in the community, families and carers play a central role in proving the on-going care and supports to people with ID (Vanegas & Abdelrahim, 2016). While there have been significant developments in models of care in many countries across the world that have brought about positive benefits to the lives of people with ID, the extent to which they have led to opportunities for self-determination and decision-making remains open to debate (Chou, Wehmeyer, Palmer, & Lee, 2017; Shogren, Wehmeyer, Lassmann, & Forber-Pratt, 2017). However, despite such wide-spread policy initiatives, there has been resistance from some parents and families to deinstitutionalisation who view them as not offering the necessary care, support and protection for their family member (McConkey, Keogh, Bunting, Garcia Iriarte, & Watson, 2016; Inclusion Ireland, 2018).

Therefore, it is apparent that many issues and conflicting views remain regarding the subject area. A useful framework (Bronfenbrenner, 1979) has been used in the conceptualization of specific issues, beyond those experiences by the individual with ID and demonstrates how different systems, processes, attitudes, values and beliefs can interact to influence important aspects of the lives of people with ID (Brown & McCann, 2018).

There is clear international research evidence regarding the scope and extent of the health inequalities and health needs experienced by people with ID, including their sexuality and distinct sexual health needs (Azzopardi-Lane & Callus, 2015; Brown & McCann, 2018; Truesdale & Brown, 2017). There is growing interest in the range of supports available to parents and other caregivers of people with ID regarding sexuality issues (Yıldız & Cavkaytar, 2017). A positive way of addressing some of the issues is through sexuality education programmes aimed specifically at families and carers (Peter, Tasker, & Horn, 2015). Such programmes may take the form of knowledge and skills acquisition that aim to help families and carers explore and more fully understand the various aspects of sexual expression and needs from their own viewpoint, and the perspectives of people with ID (Gardiner & Braddon, 2009; Kok & Akyuz, 2015; Schaafsma, Stoffelen, Kok, & Curfs, 2013; Yıldız & Cavkaytar, 2017). Other areas include sexual health needs (Thompson, Stancliffe, Broom, & Wilson, 2014), the potential for exploitation and harm, including online targeting (Byrne, 2017; Chadwick, Quinn, & Fullwood, 2017), sexuality beliefs and misconceptions (Rushbrooke et al., 2014b) and how families and carers can support the expression of sexuality and the development of intimate relationships in people with ID (Fulford & Cobigo, 2018; Wilkinson, Theodore, & Raczka, 2015). The aim of this review is to explore the views and experiences of families and direct care support workers in relation to the expression of sexuality by adults with ID. Therefore, the questions of the review are:

1 What are the views and experiences of families and direct care support workers regarding the expression of the sexuality by adults with ID?
2 What are the support and development needs of families and direct care support workers regarding the expression of sexuality and adults with ID?

2. Method

2.1. Search and selection strategy

A subject librarian was enlisted to assist with the literature search strategy. The databases used in the search were CINAHL, MEDLINE, PsycINFO and Sociological Abstracts. The search terms used were: intellectual disab* OR mental retard* OR mental handicap OR developmental disab* OR learning disab* AND sexuality OR famil* OR carer* OR support worker*. The inclusive dates were May 1998 to June 2018. An example of the search strategy used in one electronic database is shown in Table 1.

The inclusion criteria for the searches were limited to academic journals, peer reviewed empirical studies, and written in English. The studies had to focus specifically on the views and experiences of families and direct care support workers regarding the

Table 1
PsycINFO search strategy and results example.

Search code	Query	Results
S1	intellectual disab*	32766
S2	mental retard*	44,656
S3	mental handicap	3,605
S4	developmental disab*	36,993
S5	learning disab*	31,559
S6	S1 OR S2 OR S3 OR S4 OR S5	100,506
S7	sexuality	35,756
S8	famil*	507,904
S9	carer*	9,205
S10	support worker*	2,812
S11	S8 OR S9 OR S10	515,132
S12	S6 OR S7 OR S11	168
S13	Limiters: Years 1998-2018; peer reviewed papers	83

expression of sexuality of adults with ID. Studies that used a qualitative, quantitative or mixed methods approach were considered for inclusion in the review. The searches revealed 313 hits across all the databases. A PRISMA flow diagram (Fig. 1) contains the results of the search and selection process (Moher et al., 2015). A hand search was also conducted of the reference lists of the identified papers leaving a total of 11 papers for the review.

2.2. Characteristics of the studies

The data were extracted collectively by the reviewers. The 11 studies that addressed the study aim and objectives are presented in

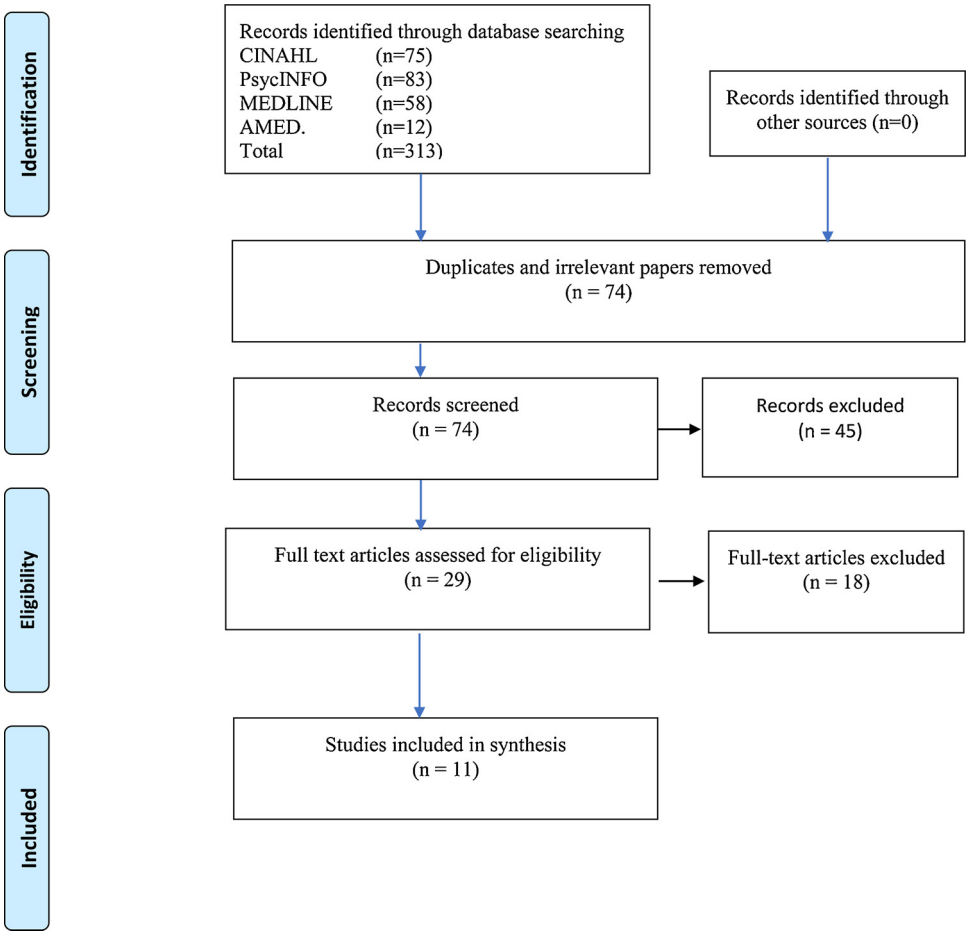

Fig. 1. PRISMA flowchart of systematic review process.

Table 3. The majority of studies (n = 3) were conducted in the United States (US). The remainder were carried out in Australia (n = 2), Canada (n = 2), Ireland (n = 1), Mexico (n = 1), Turkey (n = 1) and United Kingdom (UK) (n = 1). Of the 11 studies,

a total of 4 focused on the views and experiences of families (Ballan, 2012; Gürol, Polat, & Oran, 2014; Nichols & Blakeley-Smith, 2009; Pownall, Jahoda, Hastings, & Kerr, 2011), 4 studies on direct care support workers (Gilmore & Chambers, 2010; Pebdani, 2016; Saxe & Flanagan, 2014, 2016), and 3 combined both groups (Eastgate, Scheermeyer, van Driel, & Lennox, 2012; Evans, McGuire, Healy, & Carley, 2009; Morales, Lopez, & Mullet, 2011). Sample sizes ranged from 8 to 308 study participants and included families of people with ID and support workers involved in the day-to-day care of people with ID. All of the studies considered in the review used a selection of data collection methods that included surveys, questionnaires and interviews. A total of four studies were quantitative, adopting a range of measures and survey approaches. No controlled trials or planned intervention studies were identified. Seven studies used qualitative approaches including interviews or focus groups, and no papers utilized a mixed method design.

2.3. Quality assessment

The authors jointly reviewed and appraised the papers for methodological quality. Given the lack of controlled trials and intervention studies and the descriptive nature of data analysis, the same quality assessment tool was used as an evidence-based framework to review all papers (Critical Appraisal Skills Programme, 2013). This approach was adopted to enable the analysis and comparison of both quantitative and qualitative data and the identification of useful findings relevant to policy, practice, education and future research within the framework of a narrative review of the evidence. Specific questions were consistently applied to each of the selected studies (see Table 2). Each question was scored zero, one or two out of a possible score of 20 points. A score of zero was assigned if the paper contained no information, one if there was a moderate amount, and a score of two indicated that the question was fully addressed (Rushbrooke et al., 2014a). A total of 5 studies achieved a score of 17 or greater, indicating good quality information (Ballan, 2012; Gilmore & Chambers, 2010; Nichols & Blakeley-Smith, 2009; Pebdani, 2016; Pownall et al., 2011). A score of between 14 and 16 was given to 6 studies that showed that there were information gaps related to clarity of the aims, appropriate recruitment strategies, data collection methods, research relationships considered, ethics statements and lack of data analysis (Eastgate et al., 2012; Evans et al., 2009; Gürol et al., 2014; Morales et al., 2011; Saxe & Flanagan, 2014, 2016). All of the studies addressed the objectives of the review and therefore were deemed suitable for inclusion.

2.4. Data synthesis and analysis

The review process was guided by recognized methods involving the synthesis of mixed literature. The reviewers had intended to conduct a meta-analysis, however as a result of the wide range of differing methodological approaches used across the studies, secondary data extraction was not possible. Therefore, a narrative synthesis was selected as the most appropriate approach, relying on key word identification and text to identify the emergent themes (Popay, Roberts, & Sowden, 2006). They were grouped into concepts to allow for contrasts and comparisons to be made between themes and across studies. The themes were identified independently and then discussed, verified and agreed by all the research team, thereby seeking to address potential reviewer bias and achieve consensus (Caldwell, Henshaw, & Taylor, 2011).

2.5. Findings

Following data analysis, five main themes emerged that were: (i) attitudes of families and direct care support workers, (ii) fear of abuse, exploitation and harm, (iii) concerns about new technologies (iv) supporting developments in practice, and (v) education and training programmes.

2.6. Attitudes of families and direct care support workers

Many adults with ID continue to live at home with their families or live in supported living, with involvement from direct care support workers. The attitudes held by family members and direct care support workers has a direct effect on the ability of both adults with ID to express their sexuality and make decisions about how to express it (Gilmore & Chambers, 2010; Pebdani, 2016; Pownall et al., 2011; Saxe & Flanagan, 2016). A recurring theme across some studies was the ability and confidence of family members to discuss sexual matters, with the need for access to education, training and support to develop their skills (Ballan, 2012; Gürol et al., 2014; Nichols & Blakeley-Smith, 2009). Direct care support workers were more likely to actively discuss sexuality and relationship issues, concerns and needs directly with the adults with ID than family members, with differences in attitudes, values and beliefs identified between older and younger support workers (Evans et al., 2009; Gilmore & Chambers, 2010). Across studies involving both families and direct care support workers, diverse views were held regarding the expression of sexuality by adults with ID, including the need to enable and fully support sexual expression and relationship aspirations (Evans et al., 2009; Gilmore & Chambers, 2010; Morales et al., 2011; Pebdani, 2016; Saxe & Flanagan, 2016).

2.7. Fear of abuse, exploitation and harm

Both families and direct care support workers were of the view that adults with ID were potentially at risk of sexual exploitation and sexual abuse (Ballan, 2012; Eastgate et al., 2012; Gürol et al., 2014; Nichols & Blakeley-Smith, 2009; Pownall et al., 2011). Some

Table 2
CASP quality scores.

CASP criteria	Ballan (2012)	Eastgate et al. (2012)	Evans et al. (2009)	Gilmore and Chambers (2010)	Gürol et al. (2014)	Morales et al. (2011)	Nichols and Blakeley-Smith (2009)	Pebdani (2016)	Pownall et al. (2011)	Saxe and Flanagan (2014)	Saxe and Flanagan (2016)
1. Clear statement of aims	2	1	2	2	2	2	2	2	1	1	2
2. Appropriate methodology	2	2	2	2	2	2	2	2	2	2	2
3. Appropriate research design	2	2	2	2	2	2	2	2	2	2	2
4. Appropriate recruitment strategy	2	1	2	2	1	1	2	2	2	2	2
5. Appropriate data collection methods	2	2	2	2	1	2	2	2	2	2	2
6. Research relationships considered	0	0	0	0	0	0	1	0	0	0	0
7. Consider ethical issues	2	2	0	2	2	1	0	2	2	1	0
8. Rigorous analysis	2	2	1	2	1	2	2	2	2	2	2
9. Clear findings	2	2	2	2	2	2	2	2	2	2	2
10. Value of the research	2	2	2	2	2	2	2	2	2	2	2
Total scores out of 20	18	16	15	18	15	16	17	18	17	16	16

Table 3
Papers included in the review.

Study Citation and Country	Aims	Sample	Data collection method	Key Findings	Recommendations	CASP scores out of 20
Ballan, M. (2012) USA	Explore communication about sexuality by children with autism and their parents.	Parents (n = 18)	Semi-structured interviews	Sexual victimization greatest concern. Misconceptions around their child's sexual behavior and intent. Challenges to discussion sexual matters with professionals and the children.	Sexual decision making with children needs further research attention. More applied prevention programmes including family-based interventions to help target 'normative' sexual behaviours.	18
Eastgate et al. (2012) Australia	Identify supports regarding sexuality, relationships and abuse prevention for families and support workers.	*Interviews:* Family members (n = 7) Support workers (n = 3) *Focus groups:* Family members (n = 5) Support workers (n = 13)	Individual interviews and focus groups	People with ID are lonely, disempowered and vulnerable to abuse. New risks from the sex industry, internet and mobile phones. Gaps in sexual knowledge and sex education.	Research needed to explore internet and mobile phone risks to inform education and support programmes. Rigorous evaluation of education programmes needed. Legal and ethical issues require clarification.	16
Evans et al. (2009) Ireland	Assess the attitudes of staff and family carers to the sexuality of people with ID	Staff carers (n = 153) Family carers (n = 155)	Postal survey	Staff carers more likely to openly discuss sexuality issues with service users and suggest environmental factors as impediments to sexual expression. Attitudinal differences exist between support workers and family carers and between older and younger carers. Support workers likely to support intimate and non-intimate relationships.	Need to provide opportunities for staff and family carers to discuss sexuality issues and a need for training in the area of sexuality.	15
Gilmore and Chambers (2010) Australia	Examine attitudes of disability support workers and leisure industry staff re the sexuality of people with ID	Support workers (n = 169) Leisure industry workers (n = 50)	Attitudes to sexuality questionnaire	Both had positive attitudes to the sexuality of people with ID. Men had less control than women. Support staff cautious about parenting and people with ID. Women had less sexual freedom than those without IDs	Need guidelines and policy in practice regarding sexuality and ID. More mandatory education and training around sexuality issues for support workers and leisure industry workers.	18
Gürol et al. (2014) Turkey	Evaluate the views of mothers of children with ID regarding their children's sexual education	Mothers (n = 9)	Focus group interviews	Sexual education not given by mothers but recognized it was required and provided by rehabilitation centres. Saw children as asexual and family planning unnecessary. Concerns about sexual abuse and exploitation.	Sexual education should be provided as standard to nurses, rehabilitation centre staff and special school staff to promote sexual development and to protect from abuse.	15
Morales et al. (2011) Mexico	Explore the attitudes of families and support workers towards people with ID	Parents (n = 120) Family carers (n = 75) Support workers (n = 75)	Interviews using case vignettes	Responses to sexual expression in people with ID were: unacceptable (37%), acceptable (36%) or dependent on individual circumstances (27%).	Research into delivery and evaluation human sexual rights training programmes.	16
Nichols and Blakeley-Smith (2009) USA	Examine parental attitudes towards sexual expression in young people with ASD and evaluate the effectiveness of an education programme	Phase 1: Parents (n = 21) Phase 2: 2 Parent education groups (n = 5) in each	Focus groups Interviews and measures	Main concerns were around exploitation, safety and misinterpreted behaviours. Parents willing but felt unprepared – lacked knowledge and resources. Benefits of the education programme were getting support and guidance from other families.	More community education resources required. Education programme needs to be longer. More rigorous evaluation needed – pre, end of course and follow-up.	17

(*continued on next page*)

Table 3 (*continued*)

Study Citation and Country	Aims	Sample	Data collection method	Key Findings	Recommendations	CASP scores out of 20
Pebdani (2016) USA	Attitudes of group home workers towards sexual expression in people with ID	Group home workers (n = 71)	Questionnaire and measures	Participating in an in-service training on sexuality and ID has a positive influence on attitudes. Women had a more positive attitude to sexual rights and about an ID person's ability to exercise self-control. No policies on sexuality (50%) response.	Access to training for all employees. Need guidance and policies addressing sexual expression. Research focusing on the impact of training needed.	18
Pownall et al. (2011) UK	Explore mothers' experiences of supporting sexuality in young people with ID	Mothers (n = 8)	Interviews	Mothers experienced challenges towards enabling independence and maintaining control. Lack of opportunity for young people to meet others and form relationships. Sexual matters ignored. Mothers lacked confidence and awareness around sexuality issues and felt risks were apparent but unaware of available supports. Schools should provide sex education.	Need a better understanding of sexuality and its social contexts. Autonomy versus control. More education and support to mothers and other family members. Professionals need to be proactive in engaging with families to discuss sexuality issues.	17
Saxe and Flanagan (2014) Canada	Identify support workers attitudes towards the sexual behaviours of adults with ID	Support workers (n = 18) Non-support workers (n = 7)	Questionnaire and measures	More liberal attitudes shown by support workers where there is no religious affiliation and they are more advanced educationally. Greater acceptance of LGB sexuality but against anal intercourse.	Need to address biased attitudes in training programmes. Increased training opportunities for support workers. Need sexuality related policies.	16
Saxe and Flanagan (2016) Canada	Identify support workers confidence towards sexuality issues, education for service users, and sexuality related policies.	Support workers (n = 16)	Survey and open-ended questions	Support workers lack experience and confidence around sexuality issues. Sex education course should include prevention and protection, appropriate behaviours and positive relationships. Significant absence of sexuality related policies.	Sex education required for support workers before commencing employment. Sex education workshops for staff. Need to develop clear policies and ensure staff are familiar with them.	16

families and direct care support workers experienced dilemmas in acknowledging the rights and desires of the individual with ID to express their sexuality and form friendships and develop intimate relationships, that for some may be sexual, versus fears related to sexual exploitation and abuse (Ballan, 2012; Eastgate et al., 2012). Family members were concerned that the desire for friendships could be misconstrued and misinterpreted, thereby placing their family member with ID at risk of exploitation and abuse (Ballan, 2012; Nichols & Blakeley-Smith, 2009). Access to education that supports adults with ID to enable self-determination and develop their knowledge of risks and how to protect themselves, was seen by both families and direct care support workers as an area requiring investment and development (Nichols & Blakeley-Smith, 2009; Pebdani, 2016; Pownall et al., 2011; Saxe & Flanagan, 2016). For other family members, there was the view that providing access to education and support was not necessary and would 'encourage' their family member to more freely express their sexuality and seek new friendships and relationships (Ballan, 2012; Gürol et al., 2014). While some families acknowledged the right of their adult child to have self-determination that would enable them to develop independence and new relationships, they were thankful for the lack of skills to self-travel and manage money, which were factors that restricted choice that would perhaps protect from the risk of abuse and exploitation. Maintaining 'control' was viewed as important for some families and support workers as a means of protecting people with ID from harm and possible abuse (Ballan, 2012; Eastgate et al., 2012; Evans et al., 2009; Nichols & Blakeley-Smith, 2009).

2.8. Concerns about new technologies

Some adults with ID are lonely and socially isolated and lack social networks and friendships (Ballan, 2012; Pownall et al., 2011). Families and direct care support workers highlighted that with the advent of access to digital technologies such as the internet, tablets and mobile phones, adults with ID have new opportunities and possibilities to communicate, develop and maintain friendships (Eastgate et al., 2012). Families were of the view that such technologies can help protect adults with ID from potential harm and victimisation (Ballan, 2012). Families and direct care support workers both expressed concerns about the risks of wider access to the internet and mobile phones and the ability of some adults with ID to protect themselves from being targeted by sexual predators (Eastgate et al., 2012; Nichols & Blakeley-Smith, 2009; Saxe & Flanagan, 2016). Due to gaps in sexual knowledge and access to sex education, concerns were identified by some families and direct care support workers that some adults with ID may be placed at risk of exploitation, abuse and prostitution due to their inability to accurately interpret the true intentions of people seeking to 'befriend' them (Eastgate et al., 2012; Nichols & Blakeley-Smith, 2009).

2.9. Supporting developments in practice

Adults with ID desire relationships and intimacy, with a need for support to facilitate decision making regarding the expression of their sexuality and help protect them from potential harm (Ballan, 2012; Gürol et al., 2014; Pebdani, 2016). The scope and extent of practice was an area of concern for some direct care support workers, a situation further exacerbated by a lack of policies and guidelines within care organisations (Saxe & Flanagan, 2014). To ensure that policy frameworks are understood and embedded in routine day-today practice, it was highlighted that organisational policies and guidelines need to be included within induction and education programmes for all direct care support workers. Addressing this will help to ensure that the workers are familiar with this area of their practice and have the opportunity to discuss concerns (Saxe & Flanagan, 2014, 2016). Failure to address the policy and guideline vacuum leaves direct care support workers confused and unclear about the scope and extent of this aspect of their role, with the need for further clarity regarding legal and ethical issues and concerns (Gilmore & Chambers, 2010; Eastgate et al., 2012; Saxe & Flanagan, 2014; Pebdani, 2016; Saxe & Flanagan, 2016).

2.10. Education and training programmes

The most commonly recurring theme across the included studies was the need to develop and provide education and training opportunities. Programmes need to provide creative spaces that brings together family members and direct care support workers to discuss and explore their views, experiences and concerns and to identify ways to best help and support the family member with ID (Ballan, 2012; Evans et al., 2009; Pownall et al., 2011). Both families and direct care support workers were of the view that mandatory training regarding sexuality should be included as standard practice across disciplines, such as health, rehabilitation and special school staff and direct care support workers working for care agencies. Both groups suggested that training should enable workers to undertake their role more effectively and efficiently to the needs of adults with ID and their families (Gilmore & Chambers, 2010; Pownall et al., 2011; Ballan, 2012; Saxe & Flanagan, 2014; Gürol et al., 2014; Pebdani, 2016; Saxe & Flanagan, 2016). Both groups recommended that robust evaluation of education programmes is advocated to identify their impact and effectiveness before, during and after delivery (Eastgate et al., 2012; Morales et al., 2011; Nichols & Blakeley-Smith, 2009).

3. Discussion

The aim of this review was to elicit the views and experiences of families and direct care support workers regarding the expression of sexuality by adults with ID and to identify their support needs. A range of issues that exist in relation to the experiences and view of families and direct care support workers have been identified and the review findings highlight areas requiring attention in terms of policy, education, supports, and future research developments. *Bronfenbrenner's Ecological Model* has been used as a framework to structure and present the discussion (Bronfenbrenner, 1979). The model provides a helpful theoretical framework for the discussion

as it focuses on assets and strengths, thereby developing the understanding of the perspectives of families and direct care support workers. It also enables the identification of the aspirations of adults with ID and how they might be addressed. With a multi-systemic focus, the different elements help develop the understanding of the needs and experiences of specific populations (Institute of Medicine, 2011). The model sets out the macro, meso and micro systems that interact with each other from an environmental perspective and the impact of the factors on service systems and human behaviour (Bronfenbrenner, 1979).

3.1. Macro system

The macro system of the model relates to the overarching factors of the cultural and societal norms and their impact on the individual. This review has identified a number of issues that need to be addressed within this system. While the shift from institutional models of care in many countries has been welcome and can have a positive impact on the lives of people with ID, concerns remain of the extent to which self-determination and decision making is a reality, including the expression of their sexuality and the pleasure derived from developing an independent sexual identity and experiencing relationships and intimacy (Brown & McCann, 2018; McCann et al., 2016; Simplican et al., 2015; Sinclair, Unruh, Lindstrom, & Scanlon, 2015; Turner & Crane, 2016; Wilkinson et al., 2015; Winges-Yanez, 2014).

The theme, *attitudes of families and direct care support workers,* highlights the need for clarity and understanding for both groups of the legal and ethical context of fundamental equal human rights of adults with ID, and concerns related to the desire to protect (O'Callaghan & Murphy, 2007; Rushbrooke et al., 2014b; Schaafsma, Kok, Stoffelen, & Curfs, 2015; World Health Organisation, 2015). While it is the case that some adults with ID may at points in their lives require protection from harm, there remains a fundamental right to take risks and experience, for example relationships and intimacy, and all the consequences that may ensue (Healy, McGuire, Evans, & Carley, 2009; Bryne 2017; Whittle & Butler, 2018).

The theme, *supporting developments in practice,* has been identified in this review as a gap that needs attention and development. The absence of clear policies may inadvertently place adults with ID at risk of harm as many are sexually active yet may lack knowledge and skills required to navigate relationships, including reporting sexual abuse and exploitation (Baines, Emerson, Robertson, & Hatton, 2018; Reid, 2018). There is therefore opportunity and need to fully engage adults with ID in the future development of organisational policies and guidelines related to sexuality issues. Areas that should be addressed include autonomy and sexual decision making, sexual health, LBGT + relationships, capacity and consent, sexual abuse, protection and safeguarding, developing relationships and responding to potential risks related to use of the internet and mobile phones (Brown & McCann, 2018; Chadwick et al., 2017; McCann et al., 2016; Overmars-Marx, Thomése, Verdonschot, & Meininger, 2014; Reid, 2018). Adults with ID are sexual beings and many are sexually active, therefore policies and guidelines need to be enabling and facilitative and embedded in organisational culture and practice, while reflecting the need to protect and safeguard where indicated (Baines et al., 2018; Pebdani, 2016; Saxe & Flanagan, 2016; Franklin & Smeaton, 2018).

3.2. Micro system

The micro system element of the model sets out the personal relationships and networks of support. From an ID perspective, this may include, families, friends, peers and support workers and the availability of and the opportunity to access social support and social support networks. Two themes relate to the micro systems of the model; *fear of abuse, exploitation and harm* and *concerns about new technologies.* Families face many dilemmas regarding the right to autonomy and decision making and the risk of potential targeting and exploitation and abuse, leaving them with complex decisions to make that can limit and inhibit the opportunities for their family member with ID to develop friendships and relationships (Ballan, 2012; Amado, Stancliffe, McCarron, & McCallion, 2013; McCann et al., 2016; Brown & McCann, 2018; Whittle & Butler, 2018). However, families and direct care support workers often lack the knowledge and confidence to discuss concerns about exploitation and abuse with adults with ID and would benefit from targeted prevention programmes to help identify the necessary protective interventions that need to be in place (McCarthy et al., 2016). Concerns regarding exploitation and abuse often focus externally on strangers, yet it is necessary to recognise the risks posed by people closely associated with adults with ID, including other people with ID, who may be the perpetrators of such harm. Therefore, access to networks of support and advice are necessary for both adults with ID and their families (Bowen & Swift, 2017; Northway et al., 2013).

An emerging area within the research literature relates to the theme, *concerns about new technologies,* and the positive and negative role that these can play in placing adults with ID at risk of harm (Eastgate et al., 2012; Chadwick et al., 2017). Adults with ID want friendships, relationships, and for some, intimacy, with evidence of increasing use of social media, often with positive benefits and experiences (Sallafranque-St-Louis & Normand, 2017; Brown & McCann, 2018; Chadwick & Fullwood, 2018). A good example is the access to friendships and dating programmes, which have been found to have a positive effect on quality of life and be effective in increasing social networks and decreasing interpersonal violence (Ward, Atkinson, Smith, & Windsor, 2013; Caton & Chapman, 2016). While positive benefits are apparent, concerns exist regarding the targeting of adults with ID through the use of, for example, social media and dating sites, which may be compounded by judgement and awareness of the risk of exploitation (Holmes & O'loughlin, 2014; Buijs, Boot, Shugar, Fung, & Bassett, 2017). Therefore, access to education and support regarding safe internet and social media use is indicated for adults with ID, their families and direct care support workers (Sanz, Gómez-Puerta, & Moltó, 2017).

3.3. Meso system

The meso system element of the model relates to the relationships and interaction between adults with ID, their families and direct care support workers and the wider macro factors. The theme, *education and training programmes,* is a significant area arising from this review. Adults with ID want access to education and support to enable them to develop and sustain relationships, friendships and experience intimacy, thereby reducing the possibility of abuse and exploitation (Murphy & O'Callaghan, 2004; Rushbrooke et al., 2014b; McCann et al., 2016; Turner & Crane, 2016; Brown & McCann, 2018). Likewise, families and direct care support workers face challenges regarding risk and autonomy and require access to education and support programmes to enable them to develop their knowledge and understanding. As part of this process, induction and development programmes for direct care support workers need to incorporate sexuality and sexual health issues, thereby ensuring that they are core to practice and effective in providing the type of support that adults with ID want and need (Rushbrooke et al., 2014b). Families too, want access to education programmes that builds upon their knowledge and confidence to help them to have sensitive conversations with their family member with ID (Kok & Akyuz, 2015; Yıldız & Cavkaytar, 2017). Central to the development, implementation and evaluation of education and development programmes is the inclusion of adults with ID. At present this is lacking, with a need to be explicit regarding how the outcomes achieved impact on their sexual lives (Schaafsma et al., 2015; Schaafsma, Kok, Stoffelen, & Curfs, 2017).

3.4. Future research directions

This review has identified a number of areas that require to be addressed to effectively support the sexuality needs of adults with ID. It is evident that there is an absence of research studies focusing on the development and implementation of policies and guidelines and of the impact, effectiveness and outcomes achieved from the education programmes that do exist. No studied were identified that focused on shared education programmes involving adults with ID, families and direct care support workers; this is an area requiring further research. No studies focused on the views and experiences of families with a family member who identified as LGBT + and their needs in relation to supporting the expression of sexuality and is another area worthy of research attention. All the studies included in this review were single centre; there were no multi-centre national or international studies, revealing the opportunity to undertake larger studies across geographical areas, countries and continents. There is therefore an opportunity and need to more fully research and understand their hopes and aspirations and the contributions and supports provided by families and direct care support workers can make in relation to the full and equal expression of their sexuality.

3.5. Strengths and limitations of the review

There is a growing interest in the sexuality needs of adults with ID and the important role that families and direct care support workers plan in enabling and inhibiting this expression. Families and direct care support workers have their own particular support and education needs that require to be met if adults with ID are to have a life that recognises and responds to all their needs, including the full expression of their sexuality in all the forms that may take. There are limitations in the existing research evidence due primarily to the small sample sizes and robustness of the study designs employed and the absence of comprehensive evaluations of education and support programmes. The authors have attempted to be rigorous in the literature identification and review process and acknowledge the potential for subjectivity.

4. Conclusion

It is apparent from this review that families and direct care support workers have specific concerns regarding the expression of sexuality by adults with ID. They also have distinct support and education needs that need to be recognised and met. Organisations involved in the care and support of adults with ID need to ensure that clear policies and guidelines are in place that are reflective of the hopes and aspirations of adults with ID regarding expressing their sexuality. Direct care support workers have an important role to play in the day-to-day lives of the adults with ID, yet there is a need for a clearer and stronger focus on the scope and extent of their role and remit in relation to enabling the exploration and expression of sexuality for the people that they care for and support. Developing evidence-based programmes that enhance the understanding of the relationship needs, hopes and aspirations of adults with ID is an area that requires attention. This can only be achieved if undertaken with people with ID at the centre of such endeavours.

Conflict of interest

The authors declared no conflict of interest

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