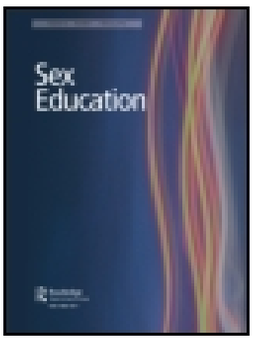

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Scoping review on sex education for high school-aged students with intellectual disability and/or on the autism spectrum: parents', teachers' and students' perspectives, attitudes and experiences

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ABSTRACT

Sex education is critical for the development of healthy sexual identity and relationships. However, students with intellectual disability and/or on the autism spectrum often receive less holistic sex education in comparison to their neurotypical counterparts. A scoping review was undertaken to determine parents', teachers' and students' perspectives, attitudes and experiences related to sex education for high school-aged students with intellectual disability and/or on the autism spectrum. Findings revealed that only a few studies consulted students themselves, while most sought only parents' and teachers' perspectives. Teachers and parents had generally positive attitudes towards sex education for students with intellectual disability and/or on the autism spectrum. However, teachers' beliefs may prevent them from delivering sex education as intended. Furthermore, parents reported a lack of confidence in discussing sexuality with their children. Well-designed, disability-inclusive education programmes that prioritise safety, assertiveness and self-determination can support positive outcomes. Removing barriers to sex education in schools, and learning from students with intellectual disability and/or on the autism spectrum what they think could improve things for themselves and peers, is key to supporting them with their needs.

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High school students; intellectual disability; autism spectrum; sex education; scoping review

Introduction

Sexuality is an important aspect of life that affects health and well-being (Flynn and Gow 2015; Lee et al. 2016; Mezones-Holguin et al. 2011; Rider et al. 2016; Syme et al. 2013). Everyone including those with disability has the right to develop and express their sexuality in an effort to lead a satisfying and fulfiling life (UNCRPD 2006). The rights of people with disability are articulated in the UN Convention on the Rights of Persons with Disabilities (UNCRPD 2006). There is also increasing recognition that people with disability should have access to good quality information on sexuality (Nelson, Odberg Pettersson,

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and Emmelin 2020). Not only does sex education contribute to the quality of life of people with disability, it also potentially reduces their vulnerability to negative sexual experiences such as exploitation and abuse (Stein, Kohut, and Dillenburger 2018; World Health Organization (WHO) 2009).

Sex education is especially pertinent to students with intellectual disability since they are up to four times more likely to be sexually abused compared to typically developing students (Barnard-Brak et al. 2014; Sullivan and Knutson 2000). Having access to a sex education programme that includes topics such as appropriate sexual behaviour and sexual socialisation could also be useful for students on the autism spectrum as such students tend to experience issues with sexual behaviour, knowledge and self-esteem, as well as limited awareness of private and public body parts, personal boundaries and safety (Dekker et al. 2015). Furthermore, many students on the autism spectrum[1] struggle with developing social relationships. While intellectual disability and autism are two different conditions, both are considered in here for several reasons. Firstly, there is a common co-occurrence of intellectual disability and autism affecting one-third to half of people on the autism spectrum. Furthermore, both populations experience factors that make them more vulnerable to abuse than mainstream population or people with other conditions (Clark and Adams 2021). Knowledge and understanding of topics related to sexuality and relationships could assist students with intellectual disability as well as students on the autism spectrum to develop meaningful, healthy and intimate relationships with others (Corona et al. 2016).

Despite the widespread acknowledgement that all young people including those with disability are entitled to sex education (Frawley and Wilson 2016; UNCRPD 2006), and general agreement of the need to provide sex education to students with intellectual disability and/or on the autism spectrum (Corona et al. 2016; Gürol, Polat, and Oran 2014), many such students continue to have limited access to sex education. It has been indicated in multiple studies that children with disabilities tend to be excluded from access to comprehensive sex education programmes (Aderemi 2014; Barnard-Brak et al. 2014; Rohleder 2010). Several barriers limit their access to these programmes.

First, there are the misperceptions and negative attitudes of parents and teachers regarding the sexuality of students with intellectual disability and/or on the autism spectrum. A common misperception of parents and teachers is that these students are asexual and childlike. Hence, it is assumed that they do not need sex education due to the assumption that they will not be involved in any sexual activity or intimate relationships (Gürol, Polat, and Oran 2014). However, research clearly indicates that students on the autism spectrum display sexual behaviours and are interested in developing romantic relationships and sexuality (Corona et al. 2016; Stokes, Newton, and Kaur 2007). Likewise, students with intellectual disability have similar sexual interests and activity to those without disability.

Students with intellectual disability and/or on the autism spectrum may also be perceived as hypersexual and lacking in ability to control their sexual urges (Neufeld et al. 2002). Sex education programme may thus not be provided to them as parents believe that learning about sexuality would not only encourage sexual behaviours (Frank and Sandman 2019), but also lead to promiscuity and risky sexual behaviour (Pownall, Jahoda, and Hastings 2012). Contrarily, sex education programmes contribute to sexual

health and reduce the risk of negative sexual experiences (Schaafsma et al. 2017; Swango-Wilson 2011).

Parents' lack of knowledge regarding their child's sexuality is another barrier to sex education of students with intellectual disability and/or on the autism spectrum (Jerman and Constantine 2010; Pownall, Jahoda, and Hastings 2012). It has been reported that the mothers of children with developmental disabilities as compared to mothers of typically developing children were unwilling to initiate conversations on sexuality and were less comprehensive on information on sexuality when such conversations occurred (Stein, Kohut, and Dillenburger 2018). This is unsurprising as research has demonstrated parents' feelings of lack of competence in helping their children with intellectual disability develop a rewarding and healthy sex life (Dupras and Dionne 2014; Pryde and Jahoda 2018). Parents reportedly feel confused and anxious regarding their child's sexuality and admit to having limited knowledge on sexuality and delivering information on sexuality to their child (Frank and Sandman 2019). Furthermore, they may have limited knowledge to adequately answer their children's questions on sexuality (Pownall, Jahoda, and Hastings 2012). Parents therefore tend to avoid talking about sexual matters until issues arise, demonstrating a reactive approach to sex education for their children with disability rather than a proactive one (Pryde and Jahoda 2018).

Another barrier derives from teachers' negative views on sex education for students with intellectual disability and/or on the autism spectrum. Frank and Sandman (2019) in a study conducted in the USA assert that teachers neither believe that sex programmes are beneficial for students with disabilities, nor is it their responsibility to deliver information on sexuality to these students. However, in an earlier investigation, Fader Wilkenfeld and Ballan (2011) found that most teachers held positive attitudes towards programmes for students with disability. Despite their positive attitudes, few teachers had delivered sex education for students with disability. Teachers also had limited training and were thus not competent in educating students with disability on topics related to sexuality and disability. It is therefore unsurprising that de Reus et al. (2015) reported teachers' lack of confidence in delivering sex education to these students. Additionally, teachers' conservative viewpoints and personal values regarding sexuality may prevent them from delivering sex programme to students as intended (Aderemi 2014). Chappell et al. (2018) in their study conducted with special school staff (educators, psychologists, and school leadership) in South Africa found that educators struggled to discuss same-sex relationships in their schools due to cultural beliefs. Moreover, educators provided fewer details to students when they believed students' capacity to understand sex education was limited (de Reus et al. 2015).

Besides parents and teachers' perceptions and attitudes, an important aspect of sex education is its content and the teaching strategies and practices used in delivering the programme. A review of the literature by Schaafsma et al. (2015) revealed that few published studies have included details on effective teaching strategies for sex education for individuals with intellectual disability. Furthermore, most do not specify the purpose and content of sex education programme for this group of individuals. Relatedly, Klett and Turan (2012) reported that few curricula and guidelines have been developed to address the needs of students on the autism spectrum regarding their sexuality. The literature on sex education of individuals with intellectual disability and on the autism spectrum also suggest that the curricula offered is not adequately comprehensive. A literature review by

Blanchett and Wolfe (2002) on sexuality curricula for individuals with intellectual disability found that while biological and reproductive health topics were covered extensively, self-advocacy and self-protection were neglected. Additionally, teachers preferred discussion of body image, relationships and decision making, and avoided content related to sexual behaviour and health. While there is limited literature detailing effective teaching strategies and practices used in sex education for students with intellectual disability and on the autism spectrum, Hanass-Hancock et al. (2018) recommends that a whole school approach be adopted to facilitate such work. The value of a whole-school approach has also been cited by others as best practice in sex education in general (Pound et al. 2017): 'that is, sex and relationships education should take place within a school context that promotes and embodies a consistent set of principles and values (e.g., the promotion of respectful interactions) within both formal and informal practices' (Pound et al. 2017, 4). This is even more crucial in the context of disability, where teaching must be tailored to unique learning and support needs (Woodcock, Dixon, and Tanner 2013).

In summary, there is consensus that students with intellectual disability and/or on the autism spectrum have the right to information related to sexuality. However, several barriers regarding sex education for this group of students have been identified, and little is known about strategies and practices that are effective for teaching in this area. Furthermore, the quality and amount of sex education that students with intellectual disability and/or on the autism spectrum receive largely depend on the perceptions and attitudes of their teachers and parents. Hence, the aim of this scoping review was to determine parents', teachers' and students' perspectives about attitudes towards, and experience with, sex education for high school students with intellectual disability and/or on the autism spectrum, as reported in primary research studies. The following questions were explored:

(1) What are students', parents', and teachers' perspectives about and attitudes to sex education for students with intellectual disability and/or on the autism spectrum?
(2) What are – according to students', parents', and teachers' – the facilitators and barriers to sex education for students with intellectual disability and/or on the autism spectrum in (high) schools?
(3) In included studies, what is the content of education programmes, what teaching strategies and practices are used, who teaching these programmes, and what are their effects on individual outcomes?

Method

This scoping review utilised Peters et al. (2015) methodological framework. This guided protocol development and the search of international literature, ensuring that both were rigorous and replicable. We restricted the review to published (peer-reviewed articles) because the goal was to identify research findings from peer-reviewed published primary research.

Scientific literature

Pilot searches were conducted in several databases before identifying the final databases and search terms, which were as follows. We searched PsycINFO, PsycARTICLES, PsycBOOKS, PsycEXTRA, PsycTESTS; Web of Science; ProQuest Education; and SCOPUS. Searches combined the following terms (Figure 1): Student* or Adolescent* or Child* or Teen* or Youth or Young Pe* or Pupil*; AND Sex* educ* or relation* educ*; AND Perspective* or Opinion* or Belie* or Attitud*; AND Intellectual dis* or Learning dis* or Developmental dis* or Developmental delay* or Cognitive impairment* or Cognitive dis* or Down syndrome* or Mental retardation; OR Autis* or Asperger* or ASD or ASC.

Inclusion and exclusion criteria

Inclusion and exclusion criteria are outlined in Table 1.

Specifically, we included articles that focused on sex education with high school students with intellectual disability and/or on the autism spectrum, including the perspectives of teachers, parents or young people themselves. The search was restricted to the English language literature. We focused on the last 10 years to ensure findings were current. The search was inclusive of all research designs (qualitative, quantitative, mixed method) so as to be comprehensive in scope.

Study selection

The search strategy generated a total of 122 records (Figure 2) and 86 records remained after excluding duplicates. Titles were screened and abstracts assessed to eliminate studies not meeting the inclusion criteria. This process resulted in 19 articles, which were read in full. At this stage, four articles were excluded for not fulfiling the inclusion criteria (e.g., the article was not primary research; the population was not high school students with intellectual disability and/or on the autism spectrum the paper described the development of a sexuality curriculum without any participants), while three articles were included after searching the reference lists of included studies, resulting in a total of 18 studies. All authors then assessed the studies for quality (Kmet, Cook, and Lee 2004) and performed the review.

Charting the data

The first author extracted the following data from each article: author(s), year, country, publication type, methodology, participants, age of the participants, focus of the study, and quality assessment (see online supplemental Table 1). All authors then used thematic analysis to analyse the articles. In doing so, a deductive approach was used, focusing specifically on: (a) students', parents', and teachers' perspectives about and attitudes to sex education for students with intellectual disability and/or on the autism spectrum; (b) facilitators and barriers to sex education for students with intellectual disability and/or on the autism spectrum in (high) schools; and (c) the content of education programmes on sexuality and

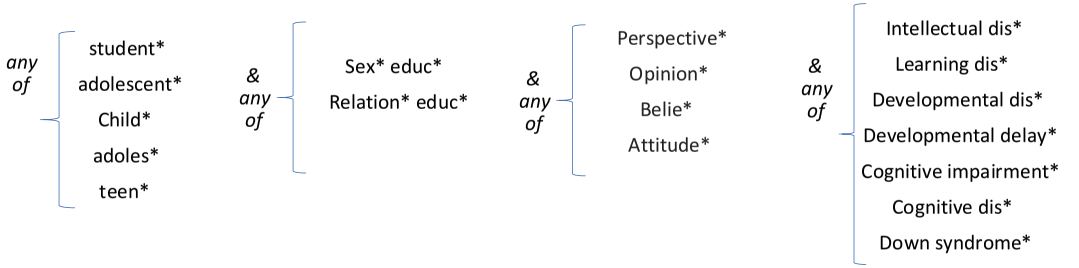

Figure 1. Search terms used to identify studies on sex education for students with intellectual disability and/or on the autism spectrum.

Table 1. Inclusion and exclusion criteria.

Inclusion criteria	Exclusion criteria
Publication type: Peer-reviewed journal papers	Publication type: Books, book chapters, literature reviews, conference papers and abstracts, editorials, commentaries, opinion and theoretical papers, observation only studies, practice guides
Language: English	Language: Any language other than English
Time period: January 2011 – May 2020	Time period: Before 2011, after May 2020
Focus: Sex education among high school students with intellectual disability and/or on the autism spectrum, including the perspectives of teachers, parents or young people with intellectual disability and/or on the autism spectrum.	Focus: Studies do not specifically focus on sex education among high school students with intellectual disability and/or on the autism spectrum.
Research design: Qualitative, quantitative and mixed research studies	Research design: Non-research studies

relationships, the teaching strategies and practices used, and who did the teaching; and evidence of impact.

Results

Summary and context of included studies

The 18 studies were published between 2011 and 2019. They included 1,976 (n = 3 to n = 1,250) participants, and were conducted in 9 countries: the USA (n = 8), the UK (n = 2), The Netherlands (n = 2), Canada (n = 1), Australia (n = 1), Sweden (n = 1), Malaysia (n = 1), Turkey (n = 1), Nigeria (n = 1), and South Africa (n = 1).

Eight studies involved young people with intellectual disability and/or on the autism spectrum (Barnard-Brak et al. 2014; Corona et al. 2016; Dekker et al. 2015; Frawley and Wilson 2016; Klett and Turan 2012; Nelson, Odberg Pettersson, and Emmelin 2020; Schaafsma et al. 2017; Visser et al. 2017), while six studies explored the perspectives of parents, mostly mothers (Dupras and Dionne 2014; Gürol, Polat, and Oran 2014; Lehan Mackin et al. 2016; Pownall, Jahoda, and Hastings 2012; Pryde and Jahoda 2018; Stein, Kohut, and Dillenburger 2018), and four studies explored the perspectives of teachers (Aderemi 2014; Ang & Lee 2016; Fader Wilkenfeld and Ballan 2011; Hanass-Hancock et al. 2018).

Students', parents', and teachers' perspectives about and attitudes to sex education

Students' perspectives

Across studies, young people with intellectual disability and on the autism spectrum reported fewer formal opportunities for sex education (Barnard-Brak et al. 2014; Frawley and Wilson 2016; Schaafsma et al. 2017). Some participants in the reviewed studies said they had not received any sex education at school (Frawley and Wilson 2016), while others reported that 'kids in [the] mainstream' received more sex education than they

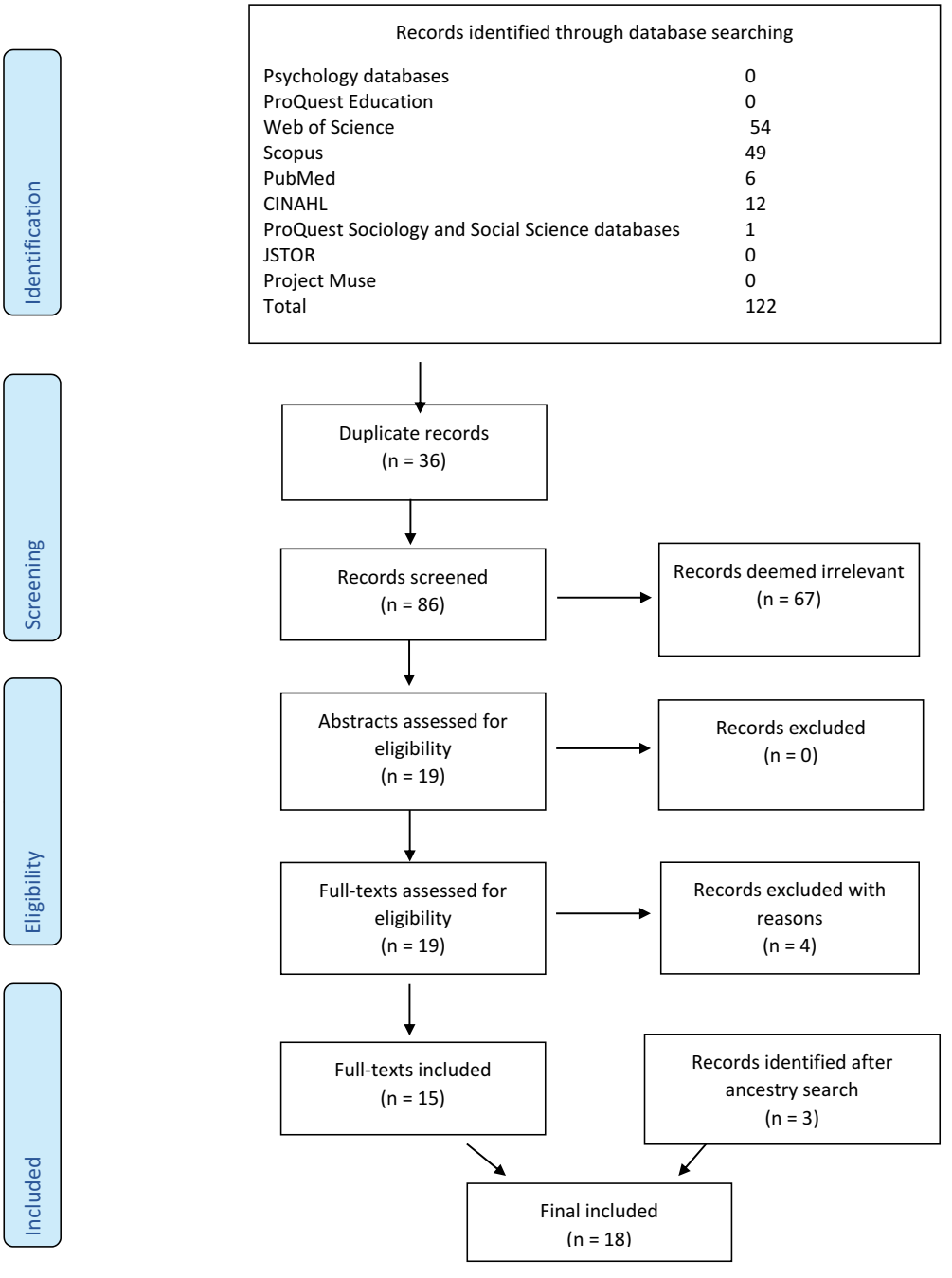

Figure 2. PRISMA flow diagram showing records identified, screened, and included.

themselves (Frawley and Wilson 2016). Others reported the receipt of some kind of sex education once or twice during their lifetime, either at school, from a parent, sibling, friend or staff member, or from other sources (e.g., from books, movies, pornography or the internet) (Frawley and Wilson 2016; Schaafsma et al. 2017). When support was

received, some reported negative experiences because information about themselves had been shared to others (Schaafsma et al. 2017).

Students also reported differences in sexual health knowledge by sex. Young men with intellectual disability had 'pockets of knowledge about sex' (e.g., masturbation, pornography) and knew the 'rules' how to treat women, but they had nowhere to check their understanding nor a space in which to practise relationships (Frawley and Wilson 2016). In some cases, as in Frawley and Wilson's (2016) study where focus groups were conducted with participants, the focus group worked as 'a men's space' to talk about these topics, with participants asking questions about how to get and keep a girlfriend, and how to relate emotionally, rather than about the mechanics of sex. In contrast, young women with intellectual disability mostly spoke about contraception and safety in relationships. Some women had good knowledge about basics of their bodies, but the decision to use contraception was often made for them by others (Frawley and Wilson 2016).

Parents' perspectives

Only one study reported that parents held negative attitudes towards sexuality and relationships for students with intellectual disability (Gürol, Polat, and Oran 2014). Parents in this study believed that their children with intellectual disability 'could not and should not have a sex life' (Gürol, Polat, and Oran 2014, 130). All other studies found that most parents were supportive of their child receiving sex education (Corona et al. 2016; Dupras and Dionne 2014; Lehan Mackin et al. 2016; Stein, Kohut, and Dillenburger 2018). Parents believed that their children were interested in intimate relationships (Corona et al. 2016) and had sexual needs (Dupras and Dionne 2014), like others without intellectual disability, but were less likely to believe that their child would be sexually active by age 18 than parents with children without intellectual disability (Stein, Kohut, and Dillenburger 2018). Parents also expressed concern about the risk of experiencing sexual abuse (Dupras and Dionne 2014; Pownall, Jahoda, and Hastings 2012) and, thus, understood the importance of providing sex education to prevent negative health consequences (Lehan Mackin et al. 2016).

Despite mostly positive beliefs, parents were unsure how to start a conversation about these topics (Corona et al. 2016), citing anxiety and discomfort in discussing sexual matters (Klett and Turan 2012; Pownall, Jahoda, and Hastings 2012) and noting the lack of resources available to address important developmental milestones (Klett and Turan 2012). What was unique in the context of intellectual disability was that parents were concerned about their children's ability to manage their sexual needs in a socially acceptable way (Dupras and Dionne 2014) and to make health-promoting decisions about contraception and readiness for sexual relationships (Pownall, Jahoda, and Hastings 2012). Some mothers of sons on the autism spectrum and an accompanying intellectual disability expressed conflicted feelings over their sons' emerging sexuality, wanting to support the development of fulfiling sexual lives and relationships on the one hand but also being frightened of sexually challenging behaviours on the other hand (Pryde and Jahoda 2018).

Teachers' perspectives

A key barrier to sex education identified in the US National Longitudinal Transition Study-2 concerned special education teachers' perceptions of its benefits (Barnard-Brak et al. 2014).

Only 25% of all special education teachers involved in this study believed that students with moderate to profound intellectual disability would gain something valuable from such a programme (Barnard-Brak et al. 2014). Putting these findings into perspective, only 68% of teachers in the study believed that students with mild intellectual disability would benefit from sex education, and 60% of teachers thought that students without intellectual disability would benefit from sex education. These findings may reflect the effect of conservative politics on sex education in the USA, which is likely to be amplified in the context of disability. Just three other studies, all of them qualitative in character, reported on teacher perceptions (Aderemi 2014; Ang & Lee 2016; Fader Wilkenfeld and Ballan 2011).

Findings from a small US study indicated that teachers were generally positive towards sex education for individuals with intellectual disability, framing sexuality as 'a normal and natural part of being human' (Fader Wilkenfeld and Ballan 2011, 355). However, teachers also recognised the need for a balance to protect one's autonomy and right to participate and experience sexual relationships while preventing victimisation (Fader Wilkenfeld and Ballan 2011).

Less accepting attitudes and beliefs were found among teachers of sex education of learners with intellectual disability in Malaysia and Nigeria (Aderemi 2014; Ang & Lee 2016). In these studies, teachers perceived students with intellectual disability to be hypersexual and incapable of forming intimate relationships, and thus, were reluctant to discuss issues related to sexuality as they were concerned that doing so would cause students to become sexually active (Aderemi 2014).

Barriers and facilitators to sex education

Barriers

A key barrier cited in the literature was the lack of good quality sexuality and relationships curricula for students with intellectual disability (Aderemi 2014). Studies also identified few resources specifically designed for students with on the autism spectrum (Lehan Mackin et al. 2016). The delivery of sex education for typically developing students was deemed inappropriate for students with intellectual disability and/or on the autism spectrum (Corona et al. 2016) and studies indicated that teachers lacked the training and skills in making such programmes more accessible (Aderemi 2014). When topics were taught, studies suggested that the information provided was either superficial or not retained, because the education students was receiving lacked depth or was too complex (Schaafsma et al. 2017). Moreover, the lack of suitable social role models added to the challenge of understanding what is socially appropriate behaviour and what is private (Fader Wilkenfeld and Ballan 2011).

Other barriers reported in the literature included the larger community context (e.g., the trauma experienced by some students, fear of transgressing cultural and religious norms) (Hanass-Hancock et al. 2018; Nelson, Odberg Pettersson, and Emmelin 2020), teachers' negative attitudes and misconceived ideas towards sexuality and relationships for students with disability (Aderemi 2014; Ang & Lee 2016; Hanass-Hancock et al. 2018; Nelson, Odberg Pettersson, and Emmelin 2020), and a lack of evidence-based practices to support teachers and parents of children with intellectual disability and on the autism spectrum regarding their sexuality (Frank and Sandman 2019; Hanass-Hancock et al. 2018). Indeed, both teachers and parents reported lacking confidence to teach sex

education because of their low levels of personal knowledge (Frank and Sandman 2019; Hanass-Hancock et al. 2018; Pryde and Jahoda 2018).

Parents also expressed uncertainty on when and how to provide sex education including what topics to cover (Dupras and Dionne 2014; Lehan Mackin et al. 2016). Mothers of sons with on the autism spectrum and intellectual disability were fearful of the potential consequences of providing information about sex (Pryde and Jahoda 2018). More traditional and cautious views of adolescents' sexual development were a stumbling block to communication about sex (Gürol, Polat, and Oran 2014; Pownall, Jahoda, and Hastings 2012). Sexuality was often described as taboo and less frequently discussed with girls, younger age groups, and those deemed less likely to understand the topics (Barnard-Brak et al. 2014; Gürol, Polat, and Oran 2014; Hanass-Hancock et al. 2018; Nelson, Odberg Pettersson, and Emmelin 2020). For instance, one study found that students with moderate to profound intellectual disability were significantly less likely to receive sex education (16.18%) compared with students with mild (44.1%) or no intellectual disability (47.5%) (Barnard-Brak et al. 2014).

Facilitators

Despite these barriers, several facilitators to sex education were noted in the literature. Teachers agreed about the need for sex education to begin during the school years – by the onset of puberty and no later than middle school, and tailored to the specific cognitive level of the students (Fader Wilkenfeld and Ballan 2011). In one study, it was found that young educators were more flexible and tended to challenge social beliefs that might otherwise prevent sex and sex education (Hanass-Hancock et al. 2018). A whole school approach, with training of all staff members and support from school principals, served as an enabling factor (Hanass-Hancock et al. 2018). Beyond the school environment, the topic of learning the same information at school and at home also came up as an important strategy (Hanass-Hancock et al. 2018; Pryde and Jahoda 2018). Parents also cited the importance of discussion with their children being 'clear, considered and explicit' (Pryde and Jahoda 2018, 172), and resources being person centred, developmentally appropriate, and relevant to strengths, limitations and the specific needs of the individual (Pryde and Jahoda 2018).

Findings from the US National Longitudinal Transition Study suggested that household income and higher levels of expressive communication and social skills were significant predictors of receipt of sex education among students with mild and moderate to profound intellectual disability (Barnard-Brak et al. 2014). Other facilitators included more progressive attitudes towards sexuality and believing that all sexual topics are equally important to teach children about, regardless of disability (Pownall, Jahoda, and Hastings 2012). In terms of the quality of sex education, an important facilitator included teachers' confidence delivering the curriculum (Aderemi 2014).

Teaching strategies and practices, and the effect of intervention on individual outcomes

Content

A common thread in the included literature was that sex education for students with intellectual disability and on the autism spectrum did not cover all the issues relating to

sexuality and was framed to suggest sex as something that was concerning and scary (Aderemi 2014; Ang & Lee 2016; Frawley and Wilson 2016; Gürol, Polat, and Oran 2014; Lehan Mackin et al. 2016; Pownall, Jahoda, and Hastings 2012; Stein, Kohut, and Dillenburger 2018). Frawley and Wilson (2016) and Schaafsma et al. (2017) found that the most common topics taught to students with intellectual disability were the importance of safe sex (e.g., condom use, contraception), the consequences of unsafe sex (e.g., STIs, unplanned pregnancies), the difference between public and private behaviours, and sexual abuse prevention (Frawley and Wilson 2016; Schaafsma et al. 2017). For women, menstrual hygiene was also commonly taught (Frawley and Wilson 2016). In contrast, there was very little discussion of sexuality from an emotional and relational perspective (e.g., being kind to each other, friendship, consent, boundaries) (Schaafsma et al. 2017).

Consistent with reports from young people, parents' prevailing educational priorities for their children included teaching about the behaviours that were acceptable in private and public spaces (Gürol, Polat, and Oran 2014; Pryde and Jahoda 2018; Stein, Kohut, and Dillenburger 2018), hygiene and menstruation (Klett and Turan 2012; Stein, Kohut, and Dillenburger 2018), and personal protection (Lehan Mackin et al. 2016; Stein, Kohut, and Dillenburger 2018). In addition, compared to those without disability, the mothers of adolescents with intellectual disability attached less importance to discussing topics related to sexual behaviour such as abstinence, contraception, and sexually transmissible infections and covered them at a later age (Pownall, Jahoda, and Hastings 2012). Other topics that parents felt students should not learn about included pornography, fetishes, and sex trafficking (Lehan Mackin et al. 2016), and Lehan Mackin et al. (2016) found that parents tended to assume that their children were heterosexual, which could curtail discussion about gender and sexual diversity. Parents in one outlier study also felt that it was unnecessary to include the topic of family planning as they perceived it to be irrelevant to children with intellectual disability (Gürol, Polat, and Oran 2014). These general perspectives was echoed by teachers, who, in one study, 'unanimously expressed ambivalence or disapproval towards pregnancy' (Fader Wilkenfeld and Ballan 2011, 357), which has profound implications for the provision of support for potential parents with intellectual disability with giving birth and raising a child.

In school settings, staff attitudes and training curricula largely dictated what was 'taught, how, and when' (Frawley and Wilson 2016, 480). For instance, Aderemi (2014) and Ang and Lee (2016) found that because of cultural and religious beliefs, teachers were reluctant to discuss sexual behaviour (e.g., abortion, sexual intercourse, masturbation) and felt more comfortable teaching about human development and interpersonal skills (e.g., physical changes during puberty, body image, friendship) and the social-sexual aspects of health, society, and culture (e.g., public and private behaviour, personal hygiene, gender identity). This resulted in the 'haphazard delivery of few topics on sexuality and HIV education' (Aderemi 2014, 255), with teachers usually discussing such topics only when they suspected that students were engaging in sexual activities. Finally, there was very little mention of the inclusion of pleasure in sex education in the literature (Frawley and Wilson 2016; Stein, Kohut, and Dillenburger 2018).

In total, just four sex education interventions for young people with intellectual disability and/or on the autism spectrum were identified in the literature. One focused

on teaching menstrual care to girls on the autism spectrum (Klett and Turan 2012), while the others provided a more comprehensive curriculum (Corona et al. 2016; Dekker et al. 2015; Visser et al. 2017). Online supplemental Table 2 provides a summary of these interventions, including content, teaching strategies, who undertook the teaching, and outcomes.

Teaching strategies

Some studies found teachers took a multidimensional approach to delivering sex education to individuals with intellectual disability and/or on the autism spectrum, including the use of diagrams, easy words, pictures, auditory stimuli, role playing with dolls, practical demonstrations, explicit skills training (e.g., using a model penis), small groups, and other teaching strategies to provide learning material in a form students could comprehend (Corona et al. 2016; Dekker et al. 2015; Fader Wilkenfeld and Ballan 2011; Frawley and Wilson 2016; Visser et al. 2017).

Other teaching strategies that suited students with intellectual disability and on the autism spectrum included giving adolescents the opportunity to practise skills such as changing a sanitary pad (Klett and Turan 2012) and interacting with peers (Visser et al. 2017) with the aim of improving both knowledge and behavioural outcomes.

Studies cited a need for group discussion with parents about the sex education provided to their children (Corona et al. 2016) and practical guides for parents (Dupras and Dionne 2014; Klett and Turan 2012), as well as workshops that included not only parents but also children with intellectual disability parents. Such approaches might encourage children to engage in conversation regarding sexuality with their parents and build positive relationships characterised by trust and listening to children (Dupras and Dionne 2014). Parents also felt supported and in control (Klett and Turan 2012).

Books and the Internet were common tools that parents used when educating their children about sex, while fewer parents sought support from an expert (Stein, Kohut, and Dillenburger 2018). Resources that they thought would be helpful in providing high-quality education included workshops with a professional, interactive websites, and videos (Stein, Kohut, and Dillenburger 2018). Parents also noted how the use of technology could also enhance their child's learning (Lehan Mackin et al. 2016).

Who taught (or should teach) the programmes?

Parents' perspectives about who should educate their children about sexuality and relationships varied. Some viewed the task as their responsibility (and this was observed regardless of disability status of children), with support from resources and workshops (Lehan Mackin et al. 2016; Stein, Kohut, and Dillenburger 2018). Others preferred medical providers to do the work (Stein, Kohut, and Dillenburger 2018). Still others believed that schools should provide sex education (Gürol, Polat, and Oran 2014; Pownall, Jahoda, and Hastings 2012). Some teachers, however, did not view educating about sexuality as their professional responsibility and assigned the task to other school-based professionals: for example, the school nurse, the physical education teacher, personal care assistants, social workers, or psychologists (Fader Wilkenfeld and Ballan 2011). Teachers in another study believed that younger teachers were more capable of responding to students' questions about sex and sexuality as they related better to their students, while others claimed that

older teachers with more experience were better suited to delivering programmes on sex education (Nelson, Odberg Pettersson, and Emmelin 2020). One study suggested that having both female and male instructors deliver education to female and male adolescents was important (Corona et al. 2016), while study of mothers' attitudes found that few mothers reported peers as an important source of information about sex for their children (Pownall, Jahoda, and Hastings 2012). This contrasts with Frawley and Wilson (2016)'s work, which highlights the importance of peer educators in helping young people with intellectual disability feel understood.

Outcomes

Studies that measured outcomes noted changes following the programme or intervention (Dekker et al. 2015; Klett and Turan 2012; Visser et al. 2017). Klett and Turan (2012) found that girls were more knowledgeable about menstrual care after the intervention, and parents were satisfied with the outcomes, although their sample was very small (n = 3). In another larger programme (n = 30), increases were observed in understanding personal boundaries, but the programme did not appear to improve the skills needed for romantic relationships or reduce problematic sexual behaviour (Dekker et al. 2015; Visser et al. 2017). Moreover, the programme was more impactful on younger participants (Visser et al. 2017).

Discussion

This scoping review highlights that while many studies have sought to examine the perspectives and attitudes of teachers and parents regarding sex education for students with intellectual disability and/or on the autism spectrum, only seven studies have consulted students themselves. This is concerning as students' input in sex education is critical to ensuring that the topics and method of delivery meet their needs and are relevant to them (Frawley and Wilson 2016). Indeed, while there is substantial research highlighting the importance of developing self-determination and self-advocacy skills among students with intellectual disability and/or on the autism spectrum in order to achieve positive post-school outcomes (Carter, Austin, and Trainor 2011; Shogren et al. 2013), these students continue to be perceived as having, and often have, limited self-determination (Strnadová 2020). Self-determination skills also mean having a voice in issues relevant to students, including sex education. Therefore, students with intellectual disability and/or on the autism spectrum should not only be participants in research related to issues relevant to them, but also engaged in the co-production of the sex education curriculum as well as research on this topic.

It was clear from many studies included in this review that parents and teachers are important gatekeepers to sex education (Pownall, Jahoda, and Hastings 2012). Moreover, both teachers and parents were found to possess generally positive attitudes towards sex education for students with intellectual disability and/or on the autism spectrum. Nevertheless, teachers' beliefs and misconceptions about these students may prevent them from delivering sex education as it is intended to (Hanass-Hancock et al. 2018). Hence, teacher education is vital to address the misconceptions as well as to equip teachers with skills in delivering sex education is an accessible way (Aderemi 2014). Pre-service and in-service teacher education programmes focusing on disability and sexuality

could foster positive attitudes and self-efficacy among future teachers in teaching sex education (Ang & Lee 2016).

Parents reported a lack of confidence in discussing sexuality with their children with intellectual disability and/or on the autism spectrum and were often reactive in their approach. Because of this, parents require support in proactively discussing sexuality with their children and in ensuring that sex education for their children is not delayed but takes place at an early age. This may potentially avoid problems from escalating and allow their children to be equipped with knowledge and skills that reduces their vulnerability to abuse (Pownall, Jahoda, and Hastings 2012).

Future research should also examine the benefits of including sex education in the Individualised Educational Plans (IEP), which should be developed by a student with disability, their teacher and parents, and other relevant stakeholders. The limited research in this areas demonstrates that student voice is also silenced when it comes to active involvement in developing these plans. Research shows that students with intellectual disability and/or on the autism spectrum often remain excluded from IEP meetings (Strnadová and Cumming 2014) or, if they are physically present, they tend to be passive participants. Importantly too, transition planning needs to follow a student-centred approach in which students have a voice about their education, including sex education (Chandroo, Strnadová, and Cumming 2018).

Limitations

A major limitation to this review concerns external validity. Since the studies varied in sample size and rigour, the degree to which the conclusions may hold true for all students with intellectual disability and/or on the autism spectrum is unclear. While we included studies from different parts of the world, including countries in Africa and Asia, and found re-occurring themes across these settings, most of the included studies were conducted in the USA. Issues related to poverty and social and cultural context likely affect students' access to and experiences of sex education, further limiting generalisability. Including only peer-reviewed articles in this scoping review was another limitation. Biases may also have arisen through our decision to focus on research studies published in abstracted and indexed journals. Given the nature of their work, many professionals working with members of this population publish in professional and practice journals which may not be indexed and abstracted in the databases examined. While not research findings, some of the best practices reported in this type of literature may be relevant.

Conclusion

Teaching young people about sexuality and healthy relationships can be challenging and complex, regardless of disability (Stein, Kohut, and Dillenburger 2018). This is important to recognise, as it helps normalise the experiences for teachers and parents of young people with intellectual disability and/or on the autism spectrum. Findings from this review suggest that there are limited well-designed, disability-inclusive education programmes that prioritise safety, assertiveness, and self-determination to support positive outcomes. Removing the barriers to sex education in schools and learning from students with intellectual disability and/or on the autism spectrum what they think could improve things for them and their peers, is key to supporting students' health and needs.

Note

1. Note on terminology. We respectfully acknowledge that there are differences in the ways in which people talk about disability. Some people with disability prefer person-first language, while others prefer identity-first language. We use person-first language when referring to students with intellectual disability, which reflects the predominant usage in the Australian and international context; and the term student 'on the autism spectrum', which has been recognised in the latest research (Bury et al. 2020) as one of the more acceptable terms to members of the autistic community.

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Conflicts of interest

No potential conflict of interest was reported by the author(s).

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