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Barriers to sexuality education for children and young people with disabilities in the WHO European region: a scoping review

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ABSTRACT

While sexuality education can support children and young people with disabilities in their sexual development and contribute to their wellbeing, challenges to its provision exist. This study identifies barriers to sexuality education for children and young people with disabilities in the WHO European Region via a scoping review of research published since 2006. Using the PRISMA-ScR Guidelines and predefined selection criteria, 14 studies were selected for inclusion. Together, these studies identified seven barriers to sexuality education for children and young people with disabilities, including the social misperception of people with disabilities as asexual and in need of protection which, combined with limited support for educators, resulted in noncomprehensive and normative sexuality education. Educators seemed inclined to redirect responsibility for sexuality education to others, and diversity among children and young people with disabilities, as well as cultural and religious diversity, makes it difficult to define a general approach. Finally, competing priorities related to the general health and wellbeing of children and young people with disabilities may appear to render sexuality education less important. We identify gaps in the research and highlight implications for the reduction of the barriers to sexuality education for children and young people with disabilities within the WHO European Region.

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KEYWORDS

Disability; sexuality education; Europe; children and young people; barriers

Introduction

Like all people, children and young people with disabilities develop gradually into adulthood. This process includes sexual development, which consists of an interaction between physical, cognitive, mental, social, relational, ethical, religious and cultural factors (UNFPA 2018; Murphy and Elias 2006). While sexuality education can support children and young people with disabilities in their sexual development and contribute to their health and wellbeing (Löfgren-Mårtenson 2012), many do not receive sexuality education that is oriented to their needs and development, promotes a positive image of sexuality, or aims to empower them (Holland-Hall and Quint 2017).

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 Supplemental data for this article can be accessed [here](#).

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There are strong arguments for the provision of sexuality education to children and young people with disabilities. The UN Convention on the Rights of Persons with Disabilities (2006) recognises that people with disabilities have the right to enjoy the highest attainable standard of health without discrimination. This includes their right 'to decide freely and responsibly on the number and spacing of their children and to have access to age-appropriate information, reproductive and family planning education' (United Nations 2006). By ratifying the Convention, states commit themselves to enabling people with disabilities to exercise these rights, including the provision of sexuality education.

Beyond this, children and young people with disabilities have similar needs concerning sexuality to their peers without disabilities, and research has shown that they find sexuality education helpful in responding to these needs (McCann, Marsh, and Brown 2019; Verhoef et al. 2005; Borawska-Charko, Rohleder, and Finlay 2017). Importantly, their needs may exceed those of their peers without disabilities due to disability-specific issues, such as learning how to deal with reduced privacy (Holland-Hall and Quint 2017). Incomplete and inadequate sexuality education has been identified as a main factor impeding the development and execution of the sexuality of people with disabilities (de Carvalho and da Silva 2018).

Moreover, children and young people with disabilities may be especially vulnerable to sexual ill-health. Due to their disability(ies), they may have an increased risk of acquiring sexually transmitted infections, experiencing unplanned pregnancy, and falling victim to sexualised violence (Lane, Cambridge, and Murphy 2019; Lehan Mackin et al. 2016; Sevlever, Roth, and Gillis 2013; Abells, Kirkham, and Ornstein 2016; Travers and Tincani 2010; Simpson, Andrews, and Isaac 2010). Sexuality education can mitigate these risks by empowering children and young people with disabilities and bolstering their ability to seek support (McDaniels and Fleming 2016).

Despite these arguments, research has revealed that children and young people with disabilities receive less sexuality education than their peers without disabilities. This has been demonstrated in different settings and for different disability types. McDaniels and Fleming (2016) review of studies from the USA and similar Western societies found that formal, individualised and specific forms of sexuality education for young people with intellectual disabilities are lacking. In the USA, Gray et al. (2017) found that women with cerebral palsy were less likely to receive sexuality education from their parents before the age of 18 years when compared to a nationally representative sample. In France, Mehrabi Kolibiki, Portalier, and Nasserzadeh (2015) found a significant difference between young girls (16–20 years) with and without hearing impairments in terms of the amount of sexuality-related information they received. Young people (16–24 years) with and without mobility impairment in the USA have also been found to have less access to most sources of sexuality education (Jacobs et al. 2015).

This overall lack of sexuality education for children and young people with disabilities includes a particular gap regarding disability-specific sexuality education (East and Orchard 2014; Gray et al. 2017; Akre et al. 2015; Seidel et al. 2014). For example, in a Netherlands study of persons with spina bifida, fewer than one quarter of informants reported having received information specific to their disability, such as an increased risk of latex allergy, which causes the need for information on latex-free contraception (Verhoef et al. 2005). Furthermore, in a UK study of young people with autism spectrum disorder, participants felt that they were

not presented with the necessary skills to live a safe and satisfying sex life since the teaching provided was not adapted to their learning needs (Hannah and Stagg 2016).

It is safe, therefore, to conclude that the sexual rights of children and young people with disabilities have not yet been fully recognised (Giarni 2016) and that few receive sufficient quality or developmentally appropriate sexuality education. As Campbell, Löfgren-Mårtenson, and Martino (2020) suggest, ‘Sex education is imperative to not only increasing the likelihood for people with disabilities to enjoy fulfilling romantic and sexual lives, but also to engage in safe and satisfying sexual exploration’. Several publications have shed light on the possible barriers to sexuality education, although many have focused on other populations and other topics, for example, the barriers experienced by adults (Caspar and Glidden 2001; Brown and McCann 2018; Sinclair et al. 2015; McCann, Marsh, and Brown 2019) or those encountered in other parts of the world, such as the USA (Treacy, Taylor, and Abernathy 2018). However, the additional stigma related to sexuality among children and young people as compared to adults and the specific context of the European region with its longer tradition of sexuality education – particularly in northern and western Europe – warrants an examination of the barriers to sexuality education for children and young people with disabilities within this context.

To illuminate this state of affairs, this study reviews the scientific literature on barriers to sexuality education for children and young people with disabilities in the World Health Organisation (WHO) European Region that has been published since the signing of the UN Convention on the Rights of Persons with Disabilities in 2006. It builds on, and contributes to, discussion within the recent symposium on Crippling Sex Education published in this journal (Campbell, Löfgren-Mårtenson, and Martino 2020; Bahner 2018) and takes a new materialist approach to the subject, which considers disability as something created by many different factors at both the biological and cultural levels (Feely 2016). We distinguish between concepts of impairment (i.e. functioning at the body or body part level) and disability (i.e. the outcomes of interactions between health conditions and contextual factors) (UNFPA 2018; World Health Organization 2001). However, since the study primarily focuses on contextual barriers to sexuality education, we use the term ‘disability’ throughout. Following Campbell, Löfgren-Mårtenson, and Martino (2020), we also use person-first language (i.e. ‘people with disabilities’) rather than identity-first language.

Materials and methods

This study takes the form of a scoping literature review of the barriers to sexuality education for children and young people with disabilities that implications for stakeholders to contribute to reducing these barriers. Scoping literature reviews are deemed appropriate for summarising findings from a body of knowledge that is heterogeneous in its methods and/or disciplines (Tricco et al. 2018). The review followed the PRISMA-ScR Guidelines, which provide a checklist of essential and optional reporting items to include when completing scoping reviews (Tricco et al. 2018).

Eligibility criteria

The selection of the studied articles was based on the following criteria.

Geographical region

We included studies from the 53 European and Central Asian member states of the WHO European Region since the scoping review was conducted within the framework of engagement of the German Federal Centre for Health Education (BZgA), which is the WHO Collaborating Centre for Sexual and Reproductive Health for the WHO European Region. Our systematic review was designed to build on the WHO European Region's vision on sexuality education¹ which The Centre it has been promoting for the past decade (Ketting, Brockschmidt, and Ivanova 2020; Ketting 2018; WHO Regional Office for Europe and Federal Centre for Health Education 2010). It forms the basis of a guidance document for policymakers and programmers of sexuality education for children and young people with disabilities that will be published by WHO for the European Region.

Population

Children were defined as being between 0 and 18 years of age, while young people are defined as being between 10 and 24 years of age. Studies with study populations older than this age range but that separately reported on children and young people were also included.

Time

We searched for articles that were published between December 2006 and June 2020; the start date aligns with the adoption of the Convention on the Rights of Persons with Disabilities by the UN General Assembly.

Sexuality education

While our review engaged with the definition contained in the WHO/BZgA Standards for Comprehensive/Holistic Sexuality Education,¹ it took a broader view and included articles that have examined the more general provision of information related to sexual and reproductive health, sexuality and relationships. Therefore, we use the term 'sexuality education', rather than 'comprehensive sexuality education'.

Disabilities

We followed the definition of the UN Convention on the Rights of Persons with Disabilities 2006.²

Language

We included only English-language articles published in international peer-reviewed journals with recorded impact factors.

Information sources

We searched three databases: Web of Science (which includes all indexed international peer-reviewed journals with recorded impact factors), Embase (which focuses on European research), and PubMed (which focuses on medical scientific research and includes studies on sexuality education in healthcare settings).

Search

The search syntax (see online Appendix) was built around the study's three main topics: sexuality education, children and young people, and disabilities. For each of these concepts, an extensive search syntax was constructed, which was then combined into one search. The search was repeated twice at two different time points by the same researcher (KM). Reference lists of review articles were screened to identify additional relevant papers.

Study selection

All search results were imported into EndNote. We first filtered out duplicates and then screened the articles based on their titles. Of the remaining articles, we screened first the abstracts and then the full texts for the inclusion criteria. Finally, we undertook a quality assessment (see below), which resulted in the final article selection.

Data charting process and data items

We developed a data extraction sheet in Excel, which was independently tested by two researchers who extracted data from 10 articles and compared the results. If different results were found, the researchers discussed the issue until a consensus was reached. For the remaining articles, one researcher extracted data on the following topics:

- Country/countries where the study took place
- Study objectives
- Study population (children/young people with disabilities, parent/guardians, educators, healthcare professionals, general population)
- Study population characteristics (sex, age, number of participants, type of disability)
- Study setting (home, school, housing facility, healthcare setting)
- Methodology (recruitment place and strategy, study design)
- Barriers to sexuality education

Critical appraisal of individual sources

To assess the quality of the primary research papers, we used the Mixed Methods Appraisal Tool (MMAT; Hong et al. 2018), which can be applied to quantitative, qualitative and mixed-methods research. We applied a score of 20% for each of the five quality criteria per type of research. Scores could be 0% (largely did not meet the quality criterion or no information was available), 10% (partly met the quality criterion), or 20% (mostly met the quality criterion). Articles scoring 50% or more were included.

Data analysis

All data related to the barriers to sexuality education were extracted from the articles (without further categorisation at this point). Subsequently, we undertook a thematic

synthesis to analyse the data: first, the data were coded in descriptive themes by KM, and, subsequently, broader analytical themes were developed as a result of discussions between the two authors.

Results

Selection of evidence sources

Figure 1 illustrates the selection of articles. The initial search generated 2,894 articles; by screening their reference lists, we identified three additional articles. After removing duplicates (838), we screened a total of 2,059 titles, thereafter excluding 1,825 articles. Our screening of abstracts resulted in the selection of 53 articles, the full text of which was then screened. Of the 17 articles selected, three were of low quality. Table 1 presents the key characteristics of the 14 selected studies.

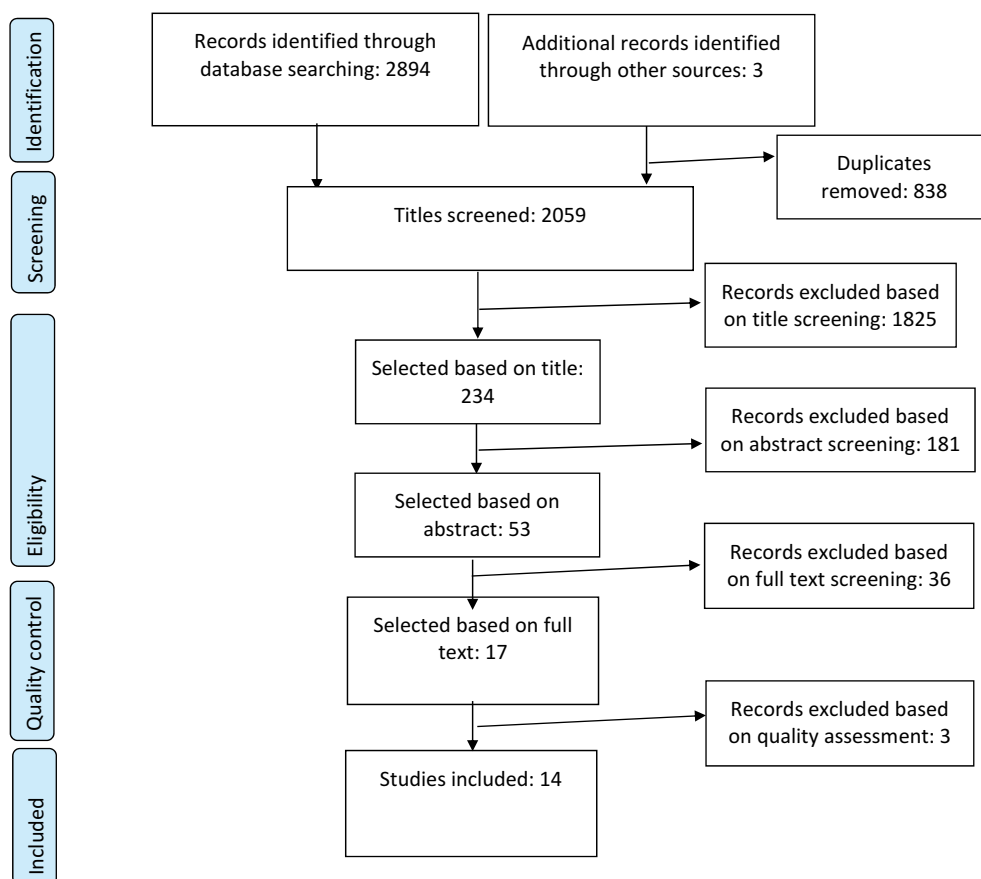


Figure 1. PRISMA flow chart detailing article selection.

Table 1. Overview of selected studies and study characteristics.

Author(s)	Title	Study objective	Country	Disability type	Study population	Study methods	MMAT score
Altundag and Calbayram (2016)	Teaching Menstrual Care Skills to Intellectually Disabled Female Students	To teach and replacement skills to intellectually disabled adolescent female students during menstruation by demonstrating on a dummy	Turkey	Intellectual and developmental disabilities	54 adolescent girls (13–17y)	Quantitative: One group pre-test and post-test model (1-month post)	60%
Bahner (2018)	Crippling Sex Education: Lessons Learned from a Programme Aimed at Young People with Mobility Impairments	To analyse sexuality and relationship education in a Swedish college programme aimed at young people with mobility impairments	Sweden	Physical disability (mobility impairment)	5 young people (18y) and 4 teachers	Qualitative: Interviews and focus group discussion	100%
Gkogkos et al. (2019)	Sexual Education: A Case Study of an Adolescent with a Diagnosis of Pervasive Developmental Disorder-Not Otherwise Specified and Intellectual Disability	To investigate the effectiveness of an intervention in helping an adolescent with pervasive developmental disorder-not otherwise specified improve appropriate sexual behaviour and minimise inappropriate behaviour	Greece	Autism spectrum disorder	1 young boy (15y) 2 parents	Mixed: Multiple-baseline across-response categories Experimental design: Semi-structured interviews	50%
Gürol, Polat, and Oran (2014)	Views of Mothers Having Children with Intellectual Disability Regarding Sexual Education: A Qualitative Study	To evaluate mothers' views on sexual education for their children with intellectual disabilities	Turkey	Intellectual and developmental disabilities	9 mothers of children aged 8–17y	Qualitative: Focus group discussion	50%
Hannah and Stagg (2016)	Experiences of Sex Education and Sexual Awareness in Young Adults with Autism Spectrum Disorder	To investigate feelings towards sex education and sexual awareness in young adults with autism spectrum disorder	UK	Autism spectrum disorder	20 young people with autism spectrum disorder (12 males, 8 females) and 20 typically developing young people (7 males, 13 females) (ages 18–25y)	Mixed: Cross-sectional survey, interviews	70%

(Continued)



Table 1. (Continued).

Author(s)	Title	Study objective	Country	Disability type	Study population	Study methods	MMAT score
Healy et al. (2009)	Sexuality and Personal Relationships for People with an Intellectual Disability, Part I: Service-User Perspectives	To assess the sexual knowledge, experiences, and aspirations of service users through focus groups and examine their perceptions of impediments to achieving sexual autonomy	Ireland	Intellectual and developmental disabilities	People 13 years old and older who make use of community-based intellectual disability services	Qualitative: Focus group discussion	100%
Kalyva (2010)	Teachers' Perspectives of the Sexuality of Children with Autism Spectrum Disorders	To examine teachers' perceptions of the sexual behaviours of children with low functioning autism, or high functioning autism, or Asperger Syndrome	Greece	Autism spectrum disorder	56 teachers (39 women, 17 men) of 76 (54 boys, 22 girls) children diagnosed with autism spectrum disorders	Quantitative: Cross-sectional survey	60%
Lafferty, McConkey, and Simpson (2012)	Reducing the Barriers to Relationships and Sexuality Education for Persons with Intellectual Disabilities	To understand how the barriers to sexuality education might be reduced	Ireland	Intellectual and developmental disabilities	100 stakeholders (26 family carers, 24 professionals, 24 frontline staff)	Qualitative: Interviews and focus group discussions	100%
Löfgren-Mårtenson (2012)	I Want to do it Right! A Pilot Study of Swedish Sex Education and Young People with Intellectual Disabilities	To strengthen sexual health among young people with intellectual disabilities and develop a knowledge base pulled from their own experiences that can help teachers in special schools to supply sufficient sex education	Sweden	Intellectual and developmental disabilities	16 young people (16–21y)	Qualitative: Interviews	100%
Löfgren-Mårtenson and Ouis (2019)	We Need 'Culture-Bridges': Professionals' Experiences of Sex Education for Pupils with Intellectual Disabilities in a Multicultural Society	To explore how sex education in special schools in Sweden is influenced and challenged by the multicultural aspects of modern society	Sweden	Intellectual and developmental disabilities	9 teachers	Qualitative: Interviews and focus group discussions	100%

(Continued)

Table 1. (Continued).

Author(s)	Title	Study objective	Country	Disability type	Study population	Study methods	MMAT score
Nelson and Odberg Pettersson (2019)	Experiences of Teaching Sexual and Reproductive Health to Students with Intellectual Disabilities	To describe what it means to teach sexual and reproductive health and rights to students with intellectual disabilities at special-needs schools in southern Sweden	Sweden	Intellectual and developmental disabilities	10 teachers	Qualitative: Interviews	100%
Pownall, Jahoda, and Hastings (2012)	Sexuality and Sex Education of Adolescents with Intellectual Disability: Mothers' Attitudes, Experiences, and Support Needs	To compare the attitudes and behaviours of mothers of young people with and without intellectual disabilities	Scotland	Intellectual and developmental disability	30 mothers of young people with and 30 of young people without intellectual disabilities	Mixed: Cross-sectional survey with open questions	60%
Visser et al. (2017)	A Randomised Controlled Trial to Examine the Effects of the Tackling Teenage Psychosexual Training Program for Adolescents with Autism Spectrum Disorder	To investigate the effects of a programme on cognitive outcomes (i.e. psychosexual knowledge, insight in interpersonal boundaries) and behavioural outcomes	The Netherlands	Autism spectrum disorder	189 young people (12–18y)	Quantitative: RCT	60%
Yildiz and Cavkaytar (2017)	Effectiveness of a Sexual Education Program for Mothers of Young Adults with Intellectual Disabilities on Mothers' Attitudes Towards Sexual Education and the Perception of Social Support	To scrutinise the effect of a sexuality education program for mothers of young adults with intellectual disabilities on the mothers' attitudes towards their children's sexuality education	Turkey	Intellectual and developmental disabilities	44 mothers	Quantitative: Quasi-experimental	60%

Characteristics of evidence sources

Most studies had taken place Sweden (4), followed by Turkey (3), the UK (3), and Greece (2). Also included were studies from The Netherlands (1) and Ireland (1). Nine studies focused on intellectual and/or developmental disabilities, four on autism spectrum disorders, and one addressed physical disabilities (mobility impairment). Most studies applied a qualitative study design with interviews and/or focus group discussions (7), while four used a quantitative design, and three used mixed methods. Five studies involved young people with disabilities themselves as the study population, while others focused on parents (3), teachers (3), or had multiple study populations (3).

Synthesis of results

We identified seven primary, closely interlinked barriers to sexuality education for children and young people with disabilities.

First, desexualising attitudes regarding the sexuality of children and young people with disabilities were commonly reported among educators.³ Gürol, Polat and Oran (2014) found that none of their respondents (nine Turkish mothers of children with intellectual and developmental disabilities) provided sexuality education to their children. In particular, mothers with daughters with intellectual or developmental disabilities felt that providing sexuality education was unnecessary since they assumed their children did not have any sexual desires or thoughts. In a study comparing mothers of children with intellectual or developmental disabilities to those of children without, Pownall, Jahoda and Hasting (2012) found that the former held more cautious attitudes about their children's readiness to learn about sex, their desire for intimate relationships, and their potential need for contraception. Furthermore, these mothers had spoken with their children about fewer sexual topics and tended to start these discussions when their children were older. Meanwhile, participants in Healy et al.'s () study reported educators' general reluctance to acknowledge and respect the sexual rights of those with intellectual or developmental disabilities (including the acceptance of intimate relationships and sexual autonomy). In some of the reported cases, these attitudes were strongly linked to cultural and religious backgrounds. For example, Lafferty, McConkey, and Simpson (2012) found that, in Northern Ireland, conservative religious beliefs significantly influenced what was considered acceptable sexual behaviour for people with intellectual or developmental disabilities.

Second, due to the increased vulnerability of children and young people with disabilities to sexual ill health, many educators' sexuality education efforts were reported to focus solely on protection rather than (also) emphasising the promotion of pleasurable sexual experiences. Vulnerability and the fear of the risk-focused side of sexuality were mentioned in several studies as important concerns for educators (Pownall, Jahoda, and Hastings 2012; Löfgren-Mårtenson 2012; Lafferty, McConkey, and Simpson 2012) and were, paradoxically, cited as reasons not to provide sexuality education.

Third, educators reported a lack of support in teaching sexuality education to children and young people with disabilities, which was reflected in their lack of training (Lafferty, McConkey, and Simpson 2012); (Kalyva 2010; Nelson and Odberg Pettersson 2019) and included the reported absence of institutional support (e.g. policies, guidelines) (Lafferty,

McConkey, and Simpson 2012). Swedish teachers also reported lack of support from other educators as a barrier to providing sexuality education to learners with intellectual and developmental disabilities (Nelson and Odberg Pettersson 2019).

Fourth, lack of support and training often resulted in embarrassment to talk about sexuality and a normative approach, which, in turn, resulted in non-comprehensive sexuality education. Swedish teachers in Nelson and Odberg Pettersson (2019)'s study described a sense of taboo around sexuality, which hindered them from comfortably talking about the issue. They reported a possible clash between teachers' personal experiences and values and learners' cultural and religious beliefs, requiring a delicate balance between teachers' ideas of right and wrong and the learners' personal values. Löfgren-Martenson et al. (2012, 2019) reported that because the educators in their Swedish study received little training, they may have reverted to their own frames of reference as the basis for content and format, which are often linked to society's prevailing restrictive values regarding the sexuality of people with intellectual or developmental disabilities. The implicit script identified in this study highlighted heterosexual norms and a preference for avoiding sexual intercourse, emphasising expressing love and friendship rather than physical sexual relationships. Nelson and Odberg Pettersson (2019) also noted that teachers tended to operate from a largely heteronormative perspective and assumed, for example, that their students were heterosexual. In Bahner's (2018) study, young people with physical disabilities considered the sexuality education they received to be insufficiently rooted in a perspective that critically considered the dominant heteronormative and ableist norms.

Fifth, unclear responsibilities among educators were reported to form another barrier. Educators involved in the lives of children and young people with disabilities seemed to redirect responsibility for sexuality education to one another; for example, Lafferty, McConkey, and Simpson (2012) observed that several respondents (family carers, frontline support workers and professional staff) devolved responsibility to external professionals – clinical psychologists, nurses and other healthcare professionals – who they felt were better equipped and more knowledgeable. Teachers in Löfgren-Mårtenson and Ouis's (2019) study stated that they were hesitant about how, when and by whom sexuality education should be conducted. This was especially prevalent when sexual norms and values were to be addressed, contributing to a certain indecisiveness among professionals.

Sixth, several studies mentioned diversity among children and young people with disabilities as a barrier to providing them with quality sexuality education. Nelson and Odberg Pettersson's (2019) informants conveyed that a class varies in both intellectual ability and sexual experience and that diversity represented a major challenge to teachers' proper balancing of the content and teaching methods applied. Cultural and religious diversity adds an additional layer to this already diverse group; for example, Löfgren-Mårtenson and Ouis (2019) respondents described how difficult it was for young people with intellectual or developmental disabilities to handle different and contradictory sexual and cultural norms in school and at home.

Finally, albeit mentioned to a lesser extent, we identified competing priorities as a barrier to sexuality education for children and young people with disabilities. Since educators of children and young people with disabilities are confronted with many other important issues related to their health and wellbeing, sexuality education is often simply de-prioritised (Gurol, Polat, and Oran 2014).

Discussion

Summary of the evidence

The present review identified 14 studies that addressed barriers to sexuality education for children and young people with disabilities in the WHO European region. While the sexuality of children and young people is already a sensitive topic, disability adds an additional layer of complexity. Disabilities can make it difficult for children and young people to access information on sexuality, for instance, because of limited capacity or opportunity to discuss matters with peers and fewer cognitive abilities to search for and filter online information.

The seven main barriers related to sexuality education for children and young people with disabilities identified in this scoping review lie at the contextual and provider levels: (1) social misperceptions of people with disabilities as asexual and (2) in need of protection, combined with (3) limited support for educators, resulting in (4) non-comprehensive and normative sexuality education. Additionally, educators seem (5) to redirect responsibility for the provision of sexuality education to one another. Furthermore, (6) diversity among children and young people with disabilities, even within one specific type of disability, is large, making a general approach difficult. This diversity in types and severity of disabilities is combined with diversity in religious and cultural backgrounds. Finally, (7) competing priorities related to the health of children and young people with disabilities may position sexuality education low down on the list of issues to be addressed.

Gaps in research

Our review revealed a paucity of relevant studies and identified several important gaps in this study field, which are important to highlight in the interpretation of the results. First, we identified studies in only six of the 53 countries of the WHO European Region. There may be several possible explanations for this: studies in other countries may be completely non-existent, published in languages other than English or published outside of the scientific literature. Furthermore, with the exception of Turkey and Greece, all studies came from northern and western European countries, which have a longer history of sexuality education (Ketting 2018). No studies were identified in Central Asia, a sub-region with a diversity of cultures and possibly different approaches to sexuality, disability and sexuality education. This aligns with findings from Ketting, Brockschmidt, and Ivanova's (2020) recent study of implementation of CSE implementation in the WHO European Region, which only identified two CSE programmes outside of northwestern Europe (in the Czech Republic and Estonia). The authors concluded that 'in southern and south-eastern Europe and in Central Asia, CSE programmes are yet to be seen' (Ketting, Brockschmidt, and Ivanova 2020); hence it is unsurprising that no programmes specifically targeting children and young people with disabilities could be identified. This is an important research gap, particularly given the important influence of culture on sexuality and disability, as well as cultural diversity in the WHO European Region.

Second, most of the studies focused on intellectual and developmental disabilities and autism spectrum disorders, highlighting a striking gap in the research of other disability types, including physical, mental, learning and sensory disabilities. It can be assumed that

children and young people with these types of disabilities also require adapted sexuality education programmes to enable them to fulfil their right to a safe and satisfying sexual life.

Third, all identified barriers related to the provider side of sexuality education, and several barriers likely also exist on the access side. While such barriers have been identified in studies from other regions, we did not find them in those from the WHO European Region.

Fourth, we found no studies focusing on younger children (i.e. younger than 13), and most studies took place in the context of schools, homes and living facilities, meaning the potentially important role of health care providers remained unclear.

Links to existing research

Our findings support those of several articles and reviews published over the past decade. In particular, the overprotection and infantilisation of people with disabilities, as well as societal perception of the sexuality of individuals with disabilities as deviant have been reported as a major barriers to their sexual health education (Seidel et al. 2014; Treacy, Taylor, and Abernathy 2018). This highlights the culturally influenced societal perceptions of disability (Wilson and Scior 2015; Munyi 2012), and, in particular, of disability in combination with sexuality (Ditchman 2017; Esmail et al. 2010; Sinclair et al. 2015). The additional intersection with age group and the general taboo in many societies regarding young people's sexuality makes this a highly sensitive topic, which is reflected in the limited literature available. The observation that many studies on sexuality, disability and young people originated from northern and western European countries that have a longer history of sexuality education and more inclusive policies than other countries in the WHO European Region, is, therefore, unsurprising (Ketting 2018; Ketting, Brockschmidt, and Ivanova 2020; Tossebro 2016; Kabatova 2018). All other barriers seem to be linked to this fundamental societal barrier: if people's sexuality, and, in particular, that of children and young people with disabilities, is not recognised or is stigmatised, the way educators address this topic and redirect responsibility to each other will be affected (McCann, Marsh, and Brown 2019). This fundamental barrier also explains the lack of training opportunities for educators and the dominance of noncomprehensive and normative approaches to sexuality education (McCann, Marsh, and Brown 2019; Seidel et al. 2014).

One unrelated barrier is the considerable diversity among children and young people with disabilities, which warrants a targeted, often individual, approach to sexuality education. Although the development of a uniform curriculum is not possible, the development process can be streamlined, and the general principles of sexuality education curriculum development (UNESCO 2018) still apply, including i) involving experts on human sexuality, behaviour change and pedagogical theory, ii) involving young people, caregivers and other stakeholders, iii) assessing the sexual reproductive health needs and behaviours of the children and young people targeted by the programme, and iv) assessing the resources (human, time and financial) available to develop and implement the curricula. Despite this, a review by Schaafsma et al. (2013) of sexuality education programmes showed they lacked specific outcomes and did not have a theoretical basis nor involve members of relevant groups in their development processes.

Implications for research, policy and programmes

Mapping the barriers to sexuality education for children and young people with disabilities is the first step in a longer process to address these barriers. To facilitate this process, we will discuss implications for future research, policies and programmes based on this scoping review.

Given the paucity of published scientific research in this area, further evidence is required on the barriers to sexuality education for children and young people with disabilities within Europe, in particular regarding different types of disabilities, the role of the healthcare sector, disability-specific barriers and younger children. Further, considering the difficulties inherent in research with minors with disabilities – especially related to random sampling and reaching a sample size that allows statistically relevant conclusions – we recommend mixed-methods research using quantitative and qualitative data to gain more in-depth insight.

Existing barriers to sexuality education for children and young people with disabilities can be reduced if changes are made on the societal, institutional and programme levels, as follows.

Societal level

Negative attitudes towards the sexuality of children and young people with disabilities pose a fundamental societal barrier; thus, the general population – and particularly educators working with children and young people with disabilities – should be sensitised to the fact that children and young people with disabilities are sexual beings, just like their peers without disabilities, and enjoy the same sexual rights. Raising the visibility of children and young people with disabilities in society, including their sexual needs and desires, is necessary to overcome stigma and false assumptions. In sexuality education, this could involve including children and young people with disabilities in the sexuality education materials of their peers without disabilities. According to Bahner (2018), this would 'likely hold benefits for non-disabled pupils as well, through its use of more inclusive pedagogy and in work to expand sexual possibilities'. Such societal sensitisation can substantially facilitate the implementation of other changes.

Institutional level

For future work in school, family housing facility and healthcare settings, our findings have three main implications:

- Children and young people are generally dependent on others for their sexuality-related information, and this is likely amplified among those with disabilities. Research has shown that educators of children and young people with disabilities tend to divert responsibilities to one another or feel hindered in the provision of sexuality education because of the perceived attitudes of other educators (East and Orchard 2014; Lafferty, McConkey, and Simpson 2012; Valvano et al. 2014). Clear and open discussion between parents, teachers, healthcare providers and other educators is required about their roles and responsibilities in sexuality education to ensure that it does not fall through the cracks and contradictory messages are not given.

- The development and implementation of institutional guidelines on sexuality education is required to support teachers, healthcare workers and professionals in living facilities by developing a shared understanding of the sexual development and health needs of children and young people with disabilities and clarifying the content, delivery and educator roles of sexuality education. This can help educators feel more secure and comfortable in providing sexuality education. To develop such guidelines, a generic framework developed at the regional level would be useful.
- Sexuality education is a sensitive subject, and the intersection with disability adds another layer of complexity to the situation. Expanded training in this field can support educators to develop the knowledge and skills needed to conduct high-quality sexuality education. In addition, regular supervision should be provided to support educators in their daily practice (WHO Regional Office for Europe and BZgA, 2017; Frota and Do Valle 2013).

Sexuality education programmes

While there is increasing recognition that children and young people with disabilities have similar sexual development and education needs as their peers without disabilities (Giami 2016), the focus of much work remains on protection and prevention rather than on a satisfying sexual life. Thus, a positive approach to sexuality education for children and young people with disabilities, as recommended by international guidelines (UNESCO, UNAIDS, UNFPA, UNICEF, UN Women, WHO 2018; WHO Regional Office for Europe, and Federal Centre for Health Education 2010), can enable them to perceive sexuality as a valuable resource in their lives.

Furthermore, sexuality education programmes should aim for empowerment. Since the barriers to sexuality education identified in this review lie mainly with its providers, children and young people with disabilities must be empowered to ask questions and demand information (Cwirynkalo and Zytka 2019). Empowerment also entails enabling children and young people with disabilities to make well-informed decisions regarding their sexual health and sexuality.

Given wide diversity – in disability type, developmental stage, sexual orientation, and cultural and religious background – there is no one model of sexuality education that would work for all children and young people with disabilities (Guyen and Isler 2015). Therefore, we follow Schaafsma et al. in arguing for a focus on the process of developing of sexuality education programmes, rather than proposing a generic programme that aims to serve all. As part of this process, we emphasise the importance of including children and young people with disabilities themselves (Grove et al. 2018; Bustard and Stewart 2010).

Limitations

This scoping review identified original research, intervention studies and descriptive studies that reported on various types of disabilities with differing objectives. While it provides an overview of the available evidence, it remains difficult to compare studies and draw general conclusions.

We limited ourselves to articles published in international peer-reviewed journals written in English, thereby omitting those published in non-peer-reviewed international journals, in

national journals, in other languages or in grey literature. In the linguistically diverse WHO European Region, relevant reports could have been identified in different languages in the grey literature, which could have identified additional barriers to sexuality education for children and young people with disabilities. However, we consciously chose to focus on scientific papers published in international peer-reviewed journals to provide a strong evidence base for this review.

Furthermore, we performed no double-data extraction. To align data extraction, two researchers independently extracted data from 10 articles, after which the results were compared and discussed. Thereafter, the articles were divided between the two researchers.

Conclusions

This study highlights the complexity of the interaction between people from a certain age group (children and young people), societal misperceptions (of being asexual) and a sensitive topic (sexuality). The diversity of disabilities, combined with sexual and cultural-religious diversity, adds intersections to an already complex issue. The study identified seven main barriers to sexuality education for children and young people with disabilities and highlights implications for the process of removing these barriers to allow persons with disabilities to exercise their right '[...] to have access to age-appropriate information, reproductive and family planning education' (United Nations 2006).

Notes

1. 'Sexuality education means learning about the cognitive, emotional, social, interactive and physical aspects of sexuality. Sexuality education starts early in childhood and progresses through adolescence and adulthood. For children and young people, it aims at supporting and protecting sexual development. It gradually equips and empowers children and young people with information, skills and positive values to understand and enjoy their sexuality, have safe and fulfilling relationships and take responsibility for their own and other people's sexual health and well-being. It enables them to make choices which enhance the quality of their lives and contribute to a compassionate and just society' (WHO Regional Office for Europe, and Federal Centre for Health Education 2010).
2. '[D]isability is an evolving concept and ... results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others' (United Nations 2006).
3. We use the term 'educators' to refer to all people in the lives of children and young people with disabilities who could potentially provide sexuality education, including parents, teachers, staff in housing facilities and healthcare professionals.

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