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Report

Sexual and reproductive health and rights of girls with disabilities

A review of the literature

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Sexual and reproductive health and rights of girls with disabilities

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ABSTRACT

The overall objective of the project was to carry out a literature review on sexual and reproductive health and rights (SRHR) of girls with disabilities. The review was carried out using a scoping review methodology. This report contains an introduction to the topic of the review, objectives for the review, methodology, summary of the thematic analysis of the literature, gaps in knowledge and suggestions for future research and spreadsheets of all the included literature (research articles and review articles).

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1 Background

1.1 Background to this report

This literature review on the sexual and reproductive health and rights of girls with disabilities was commissioned by the United Nations Office of the Special Rapporteur on the Rights of Persons with Disabilities. The review has been carried out by SINTEF Technology and Society and University of East London. The report contains an introduction to the topic of the review, objectives for the review, methodology, summary of the thematic analysis of the literature, gaps in knowledge and suggestions for future research and spreadsheets of all the included literature (research articles and review articles).

1.2 Introduction to the topic of research

Two concepts are central to this review, namely 'sexual health' and 'disability'. The two concepts, their definitions and how they are interlinked, are described below.

WHO (2015) describes sexual health in the following way:

Sexual health today is widely understood as a state of physical, emotional, mental and social wellbeing in relation to sexuality. It encompasses not only certain aspects of reproductive health – such as being able to control one's fertility through access to contraception and abortion, and being free from sexually transmitted infections (STIs), sexual dysfunction and sequelae related to sexual violence or female genital mutilation – but also, the possibility of having pleasurable and safe sexual experiences, free of coercion, discrimination and violence (WHO, 2015, p. 1).

In the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) (United Nations, 2006), disability is defined in the following way:

Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others (United Nations, 2006, p. 4).

However, disability is a complex and contested concept, in constant flux (Shakespeare, 2015; WHO et al., 2011), and with no unified definition (Iriarte, 2016). In the World Report on Disability (WHO et al., 2011), based on the International Classification of Functioning, Disability and Health (ICF) (WHO, 2001), disability is described in the following way:

Disability is the umbrella term for impairments, activity limitations and participation restrictions, referring to the negative aspects of the interaction between an individual (with a health condition) and that individual's contextual factors (environmental and personal factors) (WHO et al., 2011).

The strength of the ICF concept is in offering a common language to study the dynamic interaction between health condition, environmental factors and personal factors and therefore enabling to define what can improve the life situation of disabled people (Hollenweger, 2014). It looks beyond the medical condition and includes the social dimension of a person (Eide et al., 2011).

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It has been estimated that people with disabilities make up somewhere between 10% and 20% of the world's population, and of those, 80% live in low-income countries and have little or no access to basic health and social services. A higher proportion of people with disabilities live in relative poverty in both high, middle and low-income countries. It has also been estimated that there are more females than males with disabilities globally (Lancet, 2009; Shakespeare, lezzoni, & Groce, 2009; WHO & The World Bank, 2011). People with disabilities are among the most vulnerable and marginalised groups of any population, often excluded from mainstream social, economic and health services, lacking educational and occupational opportunities to meet their full potential (Eide & Loeb, 2006; Eide et al., 2011; Eide et al., 2015; Groce, 2004; Lancet, 2009; WHO & The World Bank, 2011). Stigma and prejudice are said to be one of the greatest barriers to the inclusion of people with disabilities (Groce & Trani, 2009). Worldwide women and girls with disabilities are among the most disadvantaged, with lower self-esteem, poorer health, educational and employment outcomes, and more exposure to discrimination, exploitation and abuse compared to people without disabilities in general and men and boys with disabilities more specifically (Reinkainen, 2004; Tilley, 1998; WHO & The World Bank, 2011). 'Girls with disabilities' in this review includes female children and adolescents¹ with disabilities.

All human beings are protected by the Universal Declaration of Human Rights (United Nations, 1948). Despite this, people with disabilities are denied many of their basic human rights (Harpur, 2012; Officer & Groce, 2009). The achievement of optimal sexual health for any human being is dependent on realisation of basic human rights, such as the right to non-discrimination, to privacy and confidentiality, to be free from violence and coercion, as well as the right to education, information and access to health services (United Nations, 1948; WHO, 2015). The UNCRPD includes the right to optimal sexual health (United Nations, 2006). Despite this, research evidence shows that people with disabilities are often excluded from living fully sexual and sexually healthy lives, facing a variety of structural (e.g., inaccessible facilities) and social barriers (e.g., attitudes), which restrict both the expression of their sexuality and their access to sexual and reproductive healthcare (Carew et al., 2016; Groce et al., 2013; Rohleder et al., 2009).

The sexual health of people with disabilities remains a neglected area, highlighted in the World Report on Disability (WHO & The World Bank, 2011) as a concern. It needs to be put on the research and practice agenda. This literature review focuses on the sexual and reproductive health and rights (SRHR) of girls with disabilities.

¹ WHO defines adolescents as young people between the ages of 10 and 19: http://www.who.int/topics/adolescent health/en/



2 Objectives

The overall objective of the project was to carry out a scoping review of the literature on the sexual and reproductive health and rights (SRHR) of girls with disabilities. The scoping review will;

- give an overview of available literature published in peer-reviewed journals after the year 2000
- give a summary of the thematic analysis of available literature
- give an overview of the geographical spread of the literature
- uncover gaps in the literature

3 Methodology

The goal of a literature review is to collect, analyse and present available research evidence in a given field of interest. There are several methodologies for literature reviews, some more systematic and organised than others (Arksey & O'Malley, 2005). Both systematic reviews and scoping reviews use strict, transparent methods to identify, organise and analyse all relevant literature in connection to a research question. However, scoping reviews are well suited to give an overview of a potentially large field of research and to identify gaps in knowledge, and is thus the most suitable method for the objectives of this review. This scoping review gives an overview of empirical evidence published in peer-reviewed journals related to SRHR of girls with disabilities. The review identifies issues like attitudes and stigma, including practices; access and quality of services including information, prevention and provision services (e.g. contraceptives and STIs); sexual violence; reproductive rights; best practices in ensuring sexual health; and other factors needed to promote sexual health. The scoping review was carried out according to a five-stage framework described by Arksey and O'Malley (2005):

- 1. Identifying the research questions
- 2. Identifying relevant studies
- 3. Study selection
- 4. Charting the data
- 5. Collating, summarising and reporting the results

The details of each of the five stages, and what was done in this particular review is presented below.

3.1 Identifying the research questions

The first stage of a literature review is to identify research questions, which form the basis for the next methodological steps (Arksey & O'Malley, 2005). Several different methods are useful to assist in the development of research questions and inclusion criteria for literature reviews. The PCC (Population, Concept, Context) method is the most suitable method in scoping reviews, with broad research questions and inclusion criteria (O'Connor, Green, & Higgins, 2008). Based on the objectives for this literature review, the research question is; 'what available research published in peer-reviewed journals exists after the year 2000 concerning sexual and reproductive health and rights of girls with disabilities?' Based on this research



question, the PCC method has been used to guide the literature review, primarily the inclusion and exclusion criteria for the review:

Population: The population that will be studied is girls with disabilities.

Concept: The concept or theme is sexual and reproductive health and rights among girls with disabilities. Context: The context for the review is global.

The search terms include synonyms (including truncations) and subject headings (where available) for the following search concepts: 'sexual health', 'girls with disabilities', and separate searches for 'rights'. These concepts are flexible, with more or less defined synonyms as needed. The concept of disability used in this scoping review is as broad as possible and included the following medical categorisations of disability: physical, sensory, developmental and psychosocial impairments.

3.2 Identifying relevant studies

Once research questions and search terms had been selected, relevant search engines and databases were identified. The literature review include searches in the following databases:

- PubMed
- Scopus (which includes Web of Science)
- EBSCOhost (including Academic Search Premier and PsychInfo)

The literature search only included peer-reviewed articles written in English, Norwegian or Spanish, published after the year 2000, since it is important to include evidence, which is contextually relevant today.

3.3 Study selection

3.3.1 Inclusion and exclusion criteria

To identify publications that are relevant to answer the research question(s), it is necessary to develop clear inclusion and exclusion criteria. Although these were primarily developed prior to the literature search, new criteria was also identified based on the findings from initial searches.

We searched for articles using the following search terms:

Disability OR disabled OR disabilities OR people with disabilities OR impaired OR impairment OR handicap OR mentally retarded OR mental retardation OR deaf OR blind OR spinal cord injury OR multiple sclerosis OR cerebral Palsy OR paraplegic OR quadriplegic

AND

Sexual OR sexual health OR reproductive health OR sexual abuse OR rape OR sexually transmitted diseases OR sexually transmitted infections OR sex education OR gynecology OR HIV OR sexual knowledge

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PubMed database also automatically included related terms. Only research articles published from the year 2000, and related to females, and ages up to 19 years were searched for. Even so, many were irrelevant as they dealt with adults or males only, or focused on disabling effects of HIV. Also excluded were articles which were not available in English, Norwegian or Spanish, or were not available in full text (unless the abstract contained sufficient useful information). Studies that referred to "adults" with disabilities ages 18 and up, were included as our cut-off criteria was age 19.

3.3.2 Results of the literature search

After excluding irrelevant articles and duplicates, a total of 348 articles were found. From these, non-research articles (theoretical papers, reviews, overviews, and commentaries), articles which were not available in English, Norwegian or Spanish, and articles not available in full text (and where a detailed abstract was not available) were excluded. This resulted in a total of 226 empirical research papers included in the review.



Figure 1 Flow chart showing inclusion process

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Secondary to the research papers we also identified 51 review papers that were relevant to the topic of this review. The review papers have not been included in the thematic analysis and reporting of results in this report, as they do not contain primary data. However, an overview and summary of all the identified review papers can be found in Appendix 2.

3.4 Charting the data

3.4.1 Methods used in studies

The methods used in the research papers we reviewed were:

- Case Study: 2
- Mixed Methods: 17
- Qualitative: 74
- Quantitative: 133

Thus, most papers utilized quantitative methodology, typically surveys or use of standardized questionnaires. Overall, sample sizes tended to be small and used convenience sampling (i.e. specific schools or services). There were a few national surveys (mostly from the USA) which provide valuable generalizable data. Qualitative studies provided an insight into subjective experiences of participants, but often the samples were small and non-generalizable.

3.4.1 Regions that research has been conducted in

As can be seen in the table and figure below, most of the research on girls with disabilities (specifically or as included in a population sample of young people with disabilities) that have been conducted come from North America and Western Europe. Overall, research locations is dominated by three countries: United States of America (USA), United Kingdom (UK) and South Africa. Research from South Africa reflects a body of work centred around concerns of the large HIV epidemic and the vulnerability of young people with disabilities.

| Region | N* | Specific countries |
|-----------------|----|---|
| Asia | 13 | India (5); Nepal (1); South Korea (2); Taiwan (5) |
| Eastern Europe | 5 | Lithuania (1); Poland (3); Slovenia (1) |
| Latin America | 7 | Brazil (5); Mexico (2) |
| Middle East | 13 | Iran (1); Israel (5); Turkey (7) |
| North America | 64 | Canada (14); USA (50) |
| Northern Africa | 27 | Cameroon (1); Egypt (1); Ethiopia (4); Ghana (1); Kenya (1); Nigeria (11); Rwanda (2); Sierra Leone (1); Uganda (5); |
| Oceania | 7 | Australia (7) |
| Southern Africa | 31 | Malawi (1); Mozambique (1); South Africa (28); Zimbabwe (1) |
| Western Europe | 62 | Germany (3); Ireland (3); The Netherlands (12); Norway (3); Spain (2); Sweden (9); Switzerland (1); UK (29) |

Table 1: Regions that research has been conducted in

* 1 article was across 3 countries, 1 was across 2 countries.

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The regions of Asia, Eastern Europe and Latin America remain significantly under-represented. The underrepresentation of research from many of the low- and middle-income countries of the world is a concern, given that the majority of the world's population of people with disabilities live in low and middle-income countries. Of course, it needs to be acknowledged that we reviewed papers published in peer-reviewed literature, and mostly published in English. Some studies from other regions of the world, in other languages or publications that are not peer-reviewed may be available on the internet.



Figure 2: Regions that research has been conducted in

3.4.3 Population Groups studied

The research papers we reviewed include participants who were young people with disabilities themselves, or parents, carers, teachers and health professionals working with young people with disabilities. Different terminology was used. For example, some studies (many from UK) made use of the term "learning disabilities", while others made use of the term "intellectual disabilities" or "mental retardation". Other studies used the term "developmental disabilities", which we have chosen to keep as a separate category, as it may include a physical disability (e.g. cerebral palsy), or an intellectual disability (e.g. Downs Syndrome). The specific types of disabilities that the research papers focused on were:

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- All disabilities: 43
- Autism: 6
- Behavioural (psychiatric; emotional): 8
- Developmental: 13
- Hearing: 30
- Intellectual/Learning: 93
- Physical: 46
- Visual: 15

This is represented in terms of proportional percentages in the figure below. As shown, Intellectual/learning disabilities tended to be most focused on, possibly reflecting the perceived sexual vulnerability of young people with intellectual/learning disabilities.



Figure 3: Types of disabilities focused on

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4 Summarising and reporting the results

In this section, we will give a summary of the major themes that have emerged from the review of the research literature. The majority of studies included both females and males with disabilities. We therefore use the inclusive term "young people with disabilities" in our discussion, unless where the focus is specifically on issues for girls and young women with disabilities.

4.1 Stigma

In some traditional cultures, disability may be perceived as a 'curse' (e.g. Hanass-Hancock, 2009). Women with disabilities may thus be perceived as of less value as a wife, and their sexuality goes unrecognised (Addlakha, 2007; Hanass-Hancock, 2009). Some studies suggest that the "marketability" of young women with disabilities as a spouse are compensated for by the family by ensuring they are employable and economically independent (Addlakha, 2007), or through the payment of a higher dowry (Hasan, Muhaddes, Camellia, Selim & Rashid, 2014). However, there may be cultural gender norms making some disabilities less desirable than others. In South Africa, gender norms about women needing to be submissive may result in women who are deaf being sought after as an ideal 'submissive' spouse (Hanass-Hancock, 2009). In some studies, males with disabilities are reported as being more valued in society than females with disabilities (Linton & Rueda, 2015; McKenzie, 2013).

Some parents comment on feeling that their child's sexuality and sexual behaviours are stigmatized and feared by others, and they could not envisage their child having a future partner (Ballan, 2012; McKenzie & Swartz, 2011). While parents of children with disabilities and professionals are often accepting of the sexuality of young people with disabilities (Morales, Lopez & Mullet, 2011; Wilkenfeld & Ballan, 2011), there are parents who themselves hold stigmatizing views of disability and sexuality. For example, parents may prefer their disabled child to have platonic relationships with low levels of intimacy (Evans, McGuire, Healy & Carley, 2009), or feel uncertain about the appropriateness of sexual behaviour (Swango-Wilson, 2008), or that they should not be sexual at all (Gürol, Polat & Oran, 2014) (see also findings below on parental and staff attitudes on sexual education and sexual health). Furthermore, the sexuality of young people with disabilities is often seen in heteronormative terms, with minimal attention given to other sexual orientations (Löfgren-Mårtenson, 2012; see also discussion further below).

The stigma of disability and misconceptions about disability and non-sexuality impacts negatively on young people with disabilities. Studies have reported that adolescents with disabilities feel socially isolated (Cheng & Udry, 2002) and have low self-esteem and sexual self-esteem, especially girls with disabilities (Czapla & Otrębski, 2014; Esmail, Darry, Walter & Knupp, 2010; Hilberink, Kruijver, Wiegerink, & Vliet Vlieland, 2013; Linton & Rueda, 2014; Maart & Jelsma, 2010; Maia, 2016; McKenzie & Swartz, 2011; Philander & Swartz, 2006; Yousafzai, Edwards, D'Allesandro & Lindström, 2005). Young people with disabilities, particularly girls, are more likely to be bullied (Eisenberg, Gower, McMorris & Bucchianeri, 2015; see also section below on sexual abuse). Studies have indicated that adolescents with disabilities have the same concerns about sexuality, relationships and identity, but these may be overlooked or ignored by adults, because of their disability (Chappell 2014; East & Orchard, 2014a; Healy, McGuire, Evans & Carley, 2009; Krupa & Esmail, 2010; Löfgren-Mårtenson, 2004; Maia, 2016; McKenzie & Swartz, 2011; Pinquart & Pfeiffer, 2012). While in

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some countries, young people with disabilities may understand their sexual rights, they report that various social and cultural barriers exist to their being able to achieve a fully sexual life (Healy et al., 2009; Kef & Bos, 2006; Potgieter & Khan, 2005; Rusinga, 2012; Wilkinson, Theodore & Raczka, 2015). Some young women with disabilities have reported that disability stigma makes them willing to accept a partner who may mistreat them, out of a desire to have a partner (Chappell, 2014); some young women with disabilities report that the need to be loved and accepted was for them more important than considering safe sex (Wazakili, Mpofu & Devlieger, 2006). Some young people with disabilities felt unsure of their role as a sexual partner (Czapla & Otrębski, 2014), and were anxious about disclosing their disability or aspects of their disability that affect sexuality to potential partners for fear of rejection (Heller, Gambino, Church, Lindsay, Kaufman & McPherson, 2016; Hilberink et al., 2013).

4.2 Sexual education

Young people with disabilities have been found to have low levels of sex education and sexual and reproductive health knowledge (Alemu & Fantahun, 2011; Cheng & Udry, 2002; Duh, 2000; Healy et al., 2009; Jahoda & Pownall, 2014; Kassa, Luck, Bekele & Riedel-Heller, 2016; Kijak, 2011; Liou, 2014; Miller, Pavlik, Kim & Rogers, 2017; Olandunni, 2012a; Olandunni, 2012b; Olaleye, Anoemuah, Ladipo, Delano, & Idowu, 2007; Rohleder, 2010; Shoshan, Ben-Zvi, Meyer & Katz-Leurer M, 2012; Stokes & Kaur, 2005; Touko, Mboua, Tohmuntain & Perrot, 2010; Wienholz et al., 2013), with some studies finding that females with disabilities have the lowest levels of sexual knowledge (Jahoda & Pownall, 2014). The level of knowledge may depend on the severity of disability (Barnard-Brak, Schmidt, Chesnut, Wei & Richman, 2014; Bat-chava, Martin & Kosciw, 2005; Duh, 2000). People with intellectual disabilities seem to have lowest level of sexual knowledge (Barnard-Brak et al., 2014; Kassa et al., 2016; Kijak, 2011). Some studies suggest that teachers may be making assumptions and judgements about whether a young person with intellectual disability would benefit from sexual education or not, depending on the perceived severity of disability (Barnard-Brak et al., 2014). However, studies have indicated that the 'inability' of young people with intellectual disabilities to understand may have more to do with how sexual education messages are delivered rather than the disability itself (Finlay, Rohleder, Taylor & Culfear, 2015; Lund & Hammond, 2014). However, in the case of severe intellectual disability, the severity of disability may be a factor on reduced understanding about sexuality in addition to lower levels of education (Ferguson, McKinlay & Hunt, 2002).

Young people with disabilities generally have low levels of HIV transmission and prevention knowledge, level of knowledge has been found to be lower than their non-disabled peers (Aderemi & Pillay, 2013; Aderemi, Pillay & Esterhuizen, 2013; Aderemi, Mac-Seing, Woreta & Mati, 2014; Alemu & Fantahun, 2011; Bat-Chava et al., 2005; Bisol, Sperb, Brewer, Kato & Shor-Posner, 2008; Dawood, Bhagwanjee, Govender & Chohan, 2006; DeAndrade & Baloyi, 2010; Goldstein, Eckhardt, Joyner-Creamer, et al., 2010; Groce, Yousafzai & van der Maas, 2007; Lefèvre-Chaponnière, 2010; Olaleye et al., 2007; Otte, van der Maas & de Boer, 2008; Philander & Swartz, 2006; Tobin-West & Akani, 2014; Wazakili, Mpofu & Devlieger, 2009; Wazakili et al., 2006; Yousafzai et al., 2005), and their perception of HIV risk is also generally lower (Aderemi et al., 2014; Blanchett, 2000; Kassa et al. 2016; Maart & Jelsma, 2010; Tobin-West & Akani, 2014). Although in other studies, the perception of HIV risk among youth with disabilities is higher than their non-disabled peers (Umoren & Adejumo, 2014). Females with disabilities have been found to have the lowest

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levels of HIV knowledge (Aderemi et al., 2013), although some studies have found no gender difference in level of HIV knowledge among young people with disabilities (Aderemi et al., 2014). Young people with disabilities also report less access to HIV information (Aderemi et al., 2013; Groce et al., 2007; Otte et al., 2008; Philander & Swartz, 2006; Saulo, Walakira & Darj, 2012). Where information is available, the language or format of information may not always be accessible (Alquati-Bisol, Sperb, & Moreno-Black, 2008; Bat-Chava et al., 2005; De Andrade & Baloyi, 2011; Krupa & Esmail, 2010; Yousafzai et al., 2005). Some adolescents with disabilities in mainstream schools suggest that having separate sexual education from their non-disabled peers perpetuates stigmatizing attitudes about disability and sexuality (Krupa & Esmail, 2010).

Parents and family members of children with disabilities are generally reported to be anxious, untrained and unconfident about communicating with their child about sexuality (Ballan, 2012; Bilge, Çeber, Demirelöz & Baykal Akmeşe, 2013; Dupras & Dionne, 2014; East & Orchard, 2014b; Evans et al., 2009; Isler, Beytut, Tas & Conk, 2009; Kok & Akyuz, 2015; Lafferty, McConkey & Simpson, 2012; Pownall, Jahoda & Hastings, 2012). A study from the UK (Pownall, Jahoda, Hastings & Kerr, 2011) indicated that parents are more anxious and cautious about supporting the sexuality of their child with intellectual disabilities, than supporting the sexuality of their non-disabled child. For parents of children with intellectual disabilities they report their child's ability to comprehend and behave appropriately to be a barrier to communicating with them about sexuality (Ballan, 2012; Dupras & Dionne, 2014). Parents of children with hearing impairments report communication difficulties as a barrier to discussing sexuality with their child (Mall & Swartz, 2011). Parents are reported to pass the responsibility for sexual education on to others, typically teachers (East & Orchard, 2014; Gürol et al., 2014; Isler et al., 2009; Lamorey, 2010; Povilaitiene & Radzevičiene, 2013). Other studies have found that parents seem to believe that their disabled child was not interested, or did not need, or should not receive sexual education (Clatos & Asare, 2016; Gürol et al., 2014). Staff carers may be more open to the sexuality of young people with disabilities than family carers are (Evans et al., 2009). Studies indicate that adolescents with disabilities report a lack of communication about sexuality from parents (Chappell, 2016; Hanass-Hancock, 2009; Kassa et al., 2016; Maia, 2016; Montijo, Benítez, Bautista & García, 2013), and they direct their curiosity about sexual matters to older siblings or friends (Bezerra & Pagliuca, 2010; Chappell, 2016; Olandunni, 2012a). With training, parents' attitudes towards their disabled child's sexuality can improve and their confidence in talking to their child about sexuality has been found to increase (Bilge et al., 2013; Clatos & Asare, 2016; Kok & Akyuz, 2015; Yildiz & Cavkaytar, 2017).

The extent to which sexual education at school is provided to young people with disabilities varies (Goldstein et al., 2010; Howard-Barr, Rienzo, Morgan Pigg & James, 2005; Mall & Swartz, 2014; Oladunni, 2012a; Rohleder, Swartz, Schneider & Eide, 2012; Schaafsma, Stoffelen, Kok & Curfs, 2013; Suter, McCracken & Calam, 2012). For example, in the USA, where sexual education is provided at school for young people with disabilities, it tends to be as part of an existing class on a general subject rather than provided as a separate taught subject (Gabriel & Getch, 2001). Topics that are most usually and comfortably addressed in sexual education are personal hygiene, sexual abstinence and sexual abuse (Ballan, 2012; Bezerra & Pagliuca, 2010; Mall & Swartz, 2011), while other topics related to contraception, sexual activity and sexual identity are relatively neglected (de Reus, Hanass-Hancock, Henken & van Brakel, 2015; Gabriel & Getch, 2001; Howard-Barr et al., 2005; Maia, 2016). Some young people with disabilities

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and teachers report the provision of adequate general sexual health education, but not education further to specific disability needs (Heller et al., 2016; Rueda, Linton & Williams, 2014). For example, in the USA, young people with autism (Hatton & Tector, 2010) and intellectual and developmental disabilities (Swango-Wilson, 2011) report wanting more education about friendships, intimate and sexual relationships. Teachers and other professionals report not having appropriate teaching resources and feeling unskilled in delivering education about certain sexual topics to young people with disabilities (de Reus et al., 2015; Howard-Barr et al., 2005; Lafferty et al., 2012; Lamorey, 2010; Mall & Swartz, 2012; Rueda et al., 2014; Suter, McCracken & Calam, 2009). Other difficulties reported is having a class of students with differing disabilities and severity of disabilities, making it a challenge to deliver sexual education in an accessible manner (de Reus et al., 2015). Teachers and other professionals have also reported that parents' or society's cultural or religious prohibitions around use of contraception or acceptance of masturbation, makes it difficult to deliver sexual education (Lafferty et al., 2012; Linton & Rueda, 2015; Mall & Swartz, 2014; Rohleder, 2010; Rohleder & Swartz, 2009). Within schools there may not be consensus about the delivery of sex education for students with disabilities, and school policies on sexual education for young people with disabilities may be lacking or constraining of the sexual education that teachers can deliver (Rohleder et a., 2012; Rueda et al., 2014; Schaafsma et al., 2013; Todd, 2009; Wilkenfeld & Ballan, 2011).

Sexual education has been found to be effective in improving sexual knowledge and skills (Altundağ & Çalbayram, 2016; Rodríguez, Díaz & Martínez, 2006). Studies have also found that the higher the level of sexual knowledge the less likely that adolescents would report sexual assault (Duh, 2000). Where communication ability is a barrier to education (for example for young people with intellectual disabilities), studies that have utilized alternative forms of communication (e.g. Talking Mats, board games, and Social Stories) have found these to be effective in communicating and assessing sexual health knowledge (Bell & Cameron, 2003; Klett & Turan, 2012; van der Stege, Hilberink, Bakker & van Staa, 2016; van der Stege, Hilbrink, Visser & van Staa, 2014; van der Stege, van Staa, Hilberink & Visser, 2010).

4.3 Sexual and reproductive health

Research consistently shows that young people with disabilities have sex (e.g. Jemtå, Fugl-Meyer & Öberg, 2008; Oladunni, 2012b; Olaleye et al., 2007; Umoren & Adejumo, 2014; Wiegerink et al., 2010; Wienholz et al., 2016). However, studies are inconsistent in establishing any difference in patterns of sexual behaviour between females with disabilities and non-disabled females and males with or without disabilities. Some studies find that fewer individuals with disabilities (male and female) report having ever had sex than non-disabled peers (Bisol et al., 2008; Wiegerink et al., 2010a; Wiegerink et al., 2010b; Wienholtz et al., 2013; Wienholtz et al., 2016). Other studies find that more individuals with disabilities (male and female) report having ever had sex than non-disabled peers (Aderemi & Pillay, 2013; Aderemi, et al. 2013; Brunnberg, Boström & Berglund, 2009). However, the reporting of experience of having had sex, may include coercive sex, which females with disabilities than adolescent males with disabilities report ever having had sex (Alemu & Fantahun, 2011). In some studies, adolescent girls with disabilities report having older sexual partners than non-disabled adolescent girls (Aderemi & Pillay, 2013). People with disabilities are reported to have become sexually active at a slightly younger age than their non-disabled peers, with girls with

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disabilities having first sexual experience earlier than males (Bisol et al., 2008; Kassa, Luck, Birru, Riedel-Heller, 2014; Maart & Jelsma, 2010). Other studies suggest that adolescents with visual disabilities start relationships later than their non-disabled peers (Pinquart & Pfeiffer, 2012).

Studies have also indicated that adolescents with disabilities (males and females) engage in risky sexual behaviours, such as reporting a low level of condom and contraceptive use, or having sex with a casual partner (Aderemi et al., 2013; Agarwal & Muralidhar, 2016; Alemu & Fantahun, 2011; Blanchett, 2000; Dawood et al., 2006; Kassa et al., 2014; Maart & Jelsma, 2010; Mall & Swartz, 2012; Montijo et al., 2013; Oladunni, 2012a; Olaleye et al., 2007; Shandra & Chowdhury, 2012; Touko et al., 2010) and substance use (Aderemi et al., 2013; Elliott Smith & Pick, 2015; Kassa et al., 2014; Maart & Jelsma, 2010; Mall & Swartz, 2012). Low levels of condom use may be related to low levels of self-efficacy in sexual negotiation (Dawood et al., 2006). Among adolescents with psychiatric disabilities, level of sexual risk taking may be high, particularly among girls with psychiatric disabilities (Donenberg, Wilson, Emerson & Bryant, 2002; Hadley, Barker, Lescano, et al., 2014). Higher levels of parental monitoring of young people with psychiatric disabilities and quality parent-adolescent conversations about sex is found to be associated with lower levels of sexual risk taking (Nappi et al., 2009; Wilson & Donenberg, 2004).

Some studies have looked at the prevalence of sexually transmitted infections (STIs) among youth with disabilities (Agarwal & Muralidhar, 2016). The prevalence of ever having had an STI ranged from 15.3% to 25.3% (Alemu & Fantahun, 2011; Aragão, de França, Coura, Medeiros & Enders, 2016; Kassa et al., 2014). A study from Rwanda (Munymana et al., 2014) among a sample of people with physical disabilities aged 5 to 49 found an HIV prevalence of 5.73% (higher than for the general population). In Cameroon (Touko et al., 2010), a sample of young people with hearing disabilities had an HIV prevalence of 4% (close to the prevalence rate for the general population). In a study from Brazil, people with a congenital disability have been found to be significantly more likely to have had an STI than people with an acquired disability (Aragão, de França, Coura, Medeiros & Enders, 2016). In the USA, a national study suggests that females with disabilities have higher rates of STIs than boys (Mandell et al., 2008). Few studies look at sexual dysfunctions or psychosexual problems. Children displaying traits of autism predicted more psychosexual problems in adolescents (Dekker, Hartman, Van Der Vegt, Verhulst, Van Oort & Greaves-Lord, 2015).

HIV testing was lower for young people with disabilities (males and females) than for the general population (Aderemi et al., 2014; Bat-Chava et al., 2005; Kassa et al., 2016; Tobin-West & Akani, 2014). This may depend on type of disability, with some studies finding that people with intellectual disabilities were less likely to have an HIV test (Aderemi et al., 2014). However, low levels of HIV testing has much to do with barriers to accessing relevant health services (Saulo et al. 2012).

Young people with disabilities report lower levels of access to sexual and reproductive health care services (Ahumuza, Matovu, Ddamulira & Muhanguzi, 2014; Alemu & Fantahun, 2011; Arulogun, Titiloye, Afolabi, Oyewole, Nwaorgu, 2013; Kassa et al., 2016; Kijak, 2011; Olaleye et al., 2007; Radomski, Jarząbek-Bielecka, Sowińska-Przepiera & Milewczyk, 2010; Tanabe, Nagujjah, Rimal, Bukania & Krause, 2015; Trani, Brown, Kett et al., 2011; Yousafzai et al., 2005). Women with disabilities report that their needs and expectations are not met by gynaecological services (Radomski et al., 2010; Williams, Scott & McKechanie, 2014). In a

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study in India (Agarwal & Muralidhar, 2016), only 22% of women with disabilities had regular gynaecology visits. Visit to clinics for gynaecological issues may occur at a later age, as females with certain developmental and physical disabilities have a later age of onset of menarche (Burke, Kalpakjian, Smith, Quint, 2010; Cheng & Udry, 2002; Joshi & Joshi, 2015; Kijak, 2011, Mirzaee et al., 2016). For females with certain disabilities, such as autism and intellectual disabilities, menstruation is a potentially traumatic experience, resulting in behavioural and emotional difficulties (Burke et al., 2010; Joshi & Joshi, 2015). Gynaecological clinicians are reported to feel more uncomfortable about providing gynaecological care for adolescents with disabilities (Shah, Norlin, Logsdon & Samson-Fang, 2005). In Taiwan, staff carers were reported to be able to advise women with intellectual disabilities about gynaecological issues, but did not see it as their, or the institutions responsibility (Lin, Lin, Chu & Chen, 2011; Lin, Lin, Chu & Lin, 2011). Hysterectomy for women is regarded as an effective way for treating menstrual problems. (Lin, Chen, Lin, Sung, 2011; Lin et al., 2011). Contraception is often used to treat problems with menstruation in young women with intellectual disabilities, at the request of clinicians or parents (van Schojenstein, Rook & Maaskant, 2011). For females with intellectual disabilities, contraception is often via injection, rather than administered orally (Morad, Kandel & Merrick, 2009). In the past, the sexuality of females with intellectual disabilities was often controlled through forced sterilization. However, recent research has shown that with appropriate care and support, females with intellectual disabilities can avoid unwanted pregnancies without recourse to sterilization (Roy, 2010). In India, women with disabilities had a significant lower rate of pregnancy than non-disabled women (Murthy et al., 2014).

Numerous barriers to access exist, and these include travel issues, cost, poor physical access to premises, communication difficulties, and negative attitudes of health workers (Ahumuza, Matovu, Ddamulira & Muhanguzi, 2014, Arulogun et al., 2013; Eastgate, 2005; Kassa et al. 2016; Tanabe et al., 2015; Trani et al., 2011; Yousafzai et al., 2005). For young people with hearing disabilities, the difficulty of communicating effectively with a health worker, meant that they often visited a facility accompanied by a person (usually family member) to help with communication, raising concerns about confidentiality (Arulogun, et al., 2013). Even where people with disabilities may access health care or rehabilitation, they may not always access adequate sexual counselling, or have their sexual knowledge assessed (Agarwal & Muralidhar, 2016; Thompson, Stancliffe, Broom & Wilson, 2016; Wazakili et al., 2009; Williams et al., 2014; Wilson & Frawley, 2016). Research has also found that young people with physical disabilities are less likely to discuss matters of sexual and reproductive health with health care providers than their non-disabled peers (Seburg, McMorris, Garwick & Scal, 2015). In residential facilities for people with disabilities, not all may have any specific policies or guidelines about sexual and reproductive health matters (Gust, Wang, Grot, Ransom & Levine, 2003; McConkey & Ryan, 2001). Similarly, not all sexual and reproductive health services may have policies and guidelines about the needs of people with disabilities (Mprah, Anafi & Sekyere, 2014).

A significant barrier to sexual and reproductive health care is the negative attitude of health care workers. Women with physical disabilities report negative even hostile attitudes from health workers for being pregnant (Ahumuza et al., 2014; Tanabe et al., 2015). Negative attitudes of health providers can inhibit the sexual expression of people with disabilities (O'Dea, Shuttleworth & Wedgwood, 2012). Where healthcare providers are supportive and talk openly about the sexual concerns of young people with disabilities, the

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impact on quality of life for the person with disabilities, and their sexual expression, has been found to be positive (O'Dea et al., 2012).

Clinicians and nurses who provide general interventions, report feeling concerned and unskilled at delivering interventions or assessing the sexual and reproductive health needs of women who have acquired a disability (Harris, Colantonio, Bushnik, et al., 2012) and women with intellectual disabilities (McCarthy, 2011; Thompson, Stancliffe, Wilson & Broom, 2016; Treacy & Randle, 2004). Doctors report conflicting pressures and demands from parents, families, service users and others regarding contraception and women with intellectual disabilities. Nurse practitioners may also not have enough knowledge about checking for gynaecological indications of potential sexual abuse among girls with disabilities (Koetting, Fitzpatrick, Lewin & Kilanowski, 2012). Patients with intellectual disabilities and their families bring up topics of sexual health with genetic counsellors, who may be a key professional to advocate for the sexual health of patients with disabilities (Murphy, Lincoln, Meredith, Cross and Rintell, 2016). Additionally, nurses may be well placed to support adolescents with disabilities with sexual health matters, but may be constrained from doing so by the clinical and institutional environment, where sexuality becomes medicalized (McCabe & Holmes, 2014), or constrained by parental non-consent (Treacy & Randle, 2004).

4.4 Sexual abuse

4.4.1 Vulnerability to sexual abuse

Several studies from across the world have found evidence that girls with disabilities are at increased risk for sexual violence, coercion and exploitation compared to non-disabled girls and boys with and without disabilities. It must be considered, however, that the methodology used in the various studies differs greatly and thus comparability and definite conclusions should be drawn with caution. Adding to this the definitions for abuse and for disability are different across studies, and the nature of impairment and type of abuse studied differs. Despite this, when a number of studies draws the same conclusion, it is safe to assume that there is some truth to these conclusions.

Studies from Europe, Africa, South America, North America and Asia have found that major risk factors for sexual abuse are psychiatric/ psychosocial disability, learning/ intellectual/ developmental disability, physical disability, hearing disability/ deaf, speech impairment, visual disability/ blind and substance use/ abuse. All of these groups have been found to be significantly more likely to experience various forms of sexual violence, coercion and/ or exploitation compared to their non-disabled peers. For all the groups, the risk for girls and women is consistently higher, and the prevalence is higher in the younger groups of children and adolescents compared to adults (*European studies:* Almond & Giles, 2008; Brunnberg, Boström & Berglund, 2012; Davies & Jones, 2013; Euser, Alink, Tharner, van Ijzendoorn & Bakermans-Kranenburg, 2016; Kvam, 2000; Kvam, 2004; Kvam & Loeb, 2010; Spencer, Devereux, Wallace, Sundrum, Shenoy, Bacchus & Logan, 2005; Soylu, Alpaslan, Ayaz, Esenyel & Oruç, 2013) (*African studies:* Aderemi & Pillay, 2013; Afifi, El-Lawindi, Ahmed & Basily, 2003; Devries, Kyegombe, Zuurmond, Parkes, Child, Walakira & Naker 2014) (*South American studies:* Bisol, Sperb, Brewer, Kato & Shor-Posner, 2008) (*North American studies:* Alriksson-Schmidt, Armour & Thibadeau, 2010; Anderson & Leigh, 2011; Blum, Kelly & Ireland,

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2001; Brownlie, Jabbar, Beitchman, Vida & Atkinson, 2007; Cheng & Richard, 2002; Martin, Ray, Sotres-Alvarez, Kupper, Moracco, Dickens, Scandlin & Gizlice, 2006; McGee, 2014; Mitra, Mouradian & McKenna, 2013) (*Asian studies:* Hershkowitz, Lamb & Horowitz, 2007; Mansbach-Kleinfeld, Ifrah, Apter & Farbstein, 2015; Reiter, Bryen & Shachar, 2007). The risk seems to be further increased for individuals with multiple disabilities (Brunnberg, Boström & Berglund, 2012) and severe disabilities (Caldas & Bensy, 2014; Hershkowitz, Lamb & Horowitz, 2007). Adding to this, a study from Nigeria found that girls out of school were more likely to experience all forms of violence, including sexual violence, than those in school (Arulogun, Titiloye, Oyewole, Nwaorgu & Afolabi, 2012). Studies from USA found that lower welfare status (Blum, Kelly & Ireland, 2001), being a racial minority, being unmarried (Martin, Ray, Sotres-Alvarez, Kupper., Moracco, Dickens, Scandlin & Gizlice, 2006) and being a sexual minority (McGee, 2014) were significant risk factors for sexual abuse for young girls with disabilities. In India, female victims of sexual abuse reported that while their disability was the main risk factor for abuse, other factors such as low socio-economic status and not being able to pay dowry also put them at increased risk (Hasan, Muhaddes, Camellia, Selim & Rashid, 2014).

Cultural beliefs and practices have also been highlighted as factors that expose certain groups to increased risk for sexual abuse. For instance, a South African study among carers of youth with intellectual disabilities (school staff, parents and traditional healers) described a common belief in the community saying that the spirits in people with intellectual disability were so powerful as to make another person wealthy, successful, respected and feared in the community. The belief is that for other people to benefit from this powerful spirit, they have to have sexual intercourse with the person. This puts people with intellectual disabilities cannot feel pain or pleasure, and would therefore not suffer from sexual abuse (Phasha & Myaka, 2014).

It must be noted that there are also some studies that have found slightly opposing results to the studies mentioned above. For instance, a survey among Swiss students found that the increase in risk for sexual abuse among physically disabled youth is larger for boys than for girls. In fact, once other risk factors, such as for instance child maltreatment and harsh parenting, are taken into account, physical disability is not a significant predictor for sexual violence in girls, but it remains a significant risk factor for boys (Mueller-Johnson, Eisner & Obsuth, 2014). Similarly, a study from South Africa did not find that adolescents with disabilities were at increased risk for sexual abuse compared to their abled-bodied peers (Maart & Jelsma, 2010). This was also found in a comparative study of youth with and without hearing loss in USA, but the study did find that youth with hearing loss were significantly more likely to be victims of physical abuse and weapon attacks (Titus, 2010).

4.4.2 Characteristics of sexual abuse

As shown above, girls with disabilities are more often exposed to sexual abuse compared to boys with disabilities. This may explain why studies have shown that perpetrators of sexual abuse tend to be male (Almond & Giles, 2008; Arulogun, Titiloye, Oyewole, Nwaorgu & Afolabi, 2012; Phasha & Nyokangi, 2012). Adding to this, most of the perpetrators are found to be known to the victim (Almond & Giles, 2008; Davies & Jones, 2013; Kvam, 2004; Reiter, Bryen & Shachar, 2007), for instance fathers (Arulogun, Titiloye,

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Oyewole, Nwaorgu & Afolabi, 2012), teachers (Arulogun, Titiloye, Oyewole, Nwaorgu & Afolabi, 2012; Caldas & Bensy, 2014), friends (McCormack, Kavanagh, Caffrey & Power, 2005; Phasha & Nyokangi, 2012), intimate partners (current or past) (Martin, Ray, Sotres-Alvarez, Kupper., Moracco, Dickens, Scandlin & Gizlice, 2006) or occasionally other peers with disabilities (McCormack, Kavanagh, Caffrey & Power, 2005).

The specific types of sexual violence studied and reported includes genital touching (Kvam, 2004), forced sex (Cheng & Richard, 2002; Kvam, 2004; Elliott & Pick, 2015), rape (Caldas & Bensy, 2014; Olaleye, Anoemuah, Ladipo, Delano & Idowu, 2007), unwanted intimate behaviour (Olaleye, Anoemuah, Ladipo, Delano & Idowu, 2007), verbal sexual harassment (Caldas & Bensy, 2014), intimate partner violence (Anderson & Leigh, 2011), coerced sex (Elliott & Pick, 2015) and dating violence victimization (Mitra, Mouradian & McKenna, 2013).

Some studies have found that young people with disabilities are exposed to more serious sexual abuse (sexual violence/ rape), more repeated abuses, more post-abuse pregnancies and that they have lower rates of reporting abuse (Hershkowitz, Lamb & Horowitz, 2007; Soylu, Alpaslan, Ayaz, Esenyel & Oruç, 2013; Titus, 2010).

4.4.3 Reporting sexual abuse

When it comes to discovering and reporting sexual abuse in young girls with disabilities, several challenges have been highlighted in the literature. Studies suggest that sexual abuse is often underreported, and even more so if the victim has a disability (Hershkowitz, Lamb & Horowitz, 2007; Kvam, 2004). Most of the literature on these topics concerns individuals with intellectual/ developmental disabilities, who often have reduced cognitive capacity and reduced capacity for communication, which is essential for reporting abuse and sharing their story of abuse in order to receive help and/ or to press charges against the perpetrator.

If a case of sexual abuse is taken to court, the victim usually has to be interviewed by the police, witness in court and provide a consistent and plausible account of the abuse. The victims' ability to do this determines the value placed on them as court witnesses, which in turn determines if their case is taken to court or not. Studies from Europe have found that the police lacks knowledge, good tools and guidelines for communication with individuals with intellectual/ developmental disabilities (Antaki, Richardson, Stokoe & Willott, 2015 a; b; Cederborg, Danielsson, La Rooy & Lamb, 2009; (Lindblad & Lainpelto, 2011)). The result may be that sexual abuse victims with intellectual disabilities are not regarded as trust-worthy witnesses, and their perpetrators are not prosecuted. On the other hand, a study from USA investigating mock jurors perception of adolescent sexual abuse victims found that when the victim was portrayed as having an intellectual disability, mock jurors considered their allegations as more credible and the defendant as less credible. They rated the victim as more honest and less likely to have fabricated the allegation. Mock jurors were more confident in finding the defendant guilty when the victim portrayed as having an intellectual disability (Bottoms, Nysse-Carris, Harris & Tyda, 2003).

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In the context of special schools and services for children and youth with disabilities, staff and teachers are often found to have good knowledge and awareness of the increased vulnerability for abuse faced by children and youth with various types of disabilities. This results in measures taken to help the children protect themselves from sexual abuse, including the responsibility of staff to protect disabled children (Oosterhoorn & Kendrick, 2001). At the same time, a study of professionals working in habilitation services in Sweden found that they were reluctant to report suspected cases of abuse. They worried that it would compromise their relationship with the child/ youth or their parents, that there was not enough evidence of abuse and neglect, and they were worried about the victim's future after reporting. Reporting abuse was seen as a last resort and used only when all other less punitive remedies had been exhausted. Factors that facilitated reporting were visible proof of abuse and neglect, and the disabled children's ability to communicate (Mallén, 2011). A study in South African schools reported that the organisational protocol for handling cases of sexual abuse is that cases should be handled in collaboration with the families. Sometimes the school and the family disagree on how to handle abuse, and the school often leaves it to the family. This is not always in the best interest of the victim of the abuse, especially if the perpetrator is someone in the family. The study also found that there is mistrust towards the police and justice system in many families and communities, which prevents them from reporting abuse. Some African communities prefer to deal with abuse the traditional way, outside the legal system (Phasha, 2009). Another South African study among staff in schools for adolescents with intellectual disabilities revealed tendencies for under-reporting of sexual abuse. This was due to factors such as: (a) teenagers' limited understanding and communication; (b) family's fear of stigma attached to disability; and (c) professionals' lack of expertise (Nareadi, 2013). A study from Ireland looking at patterns of disclosure and reporting of sexual abuse in intellectual disability services found that more than half of the abuse reports were made by the victims themselves, followed by family members of the victims and staff. Almost half of the abuse allegations were confirmed to be abuse through investigation (McCormack, Kavanagh, Caffrey & Power, 2005).

4.4.4 Consequences of sexual abuse

As we have seen above, there is ample evidence to indicate that there is a relationship between impairment or disability and exposure to sexual abuse. There is evidence to suggest that the reverse could also be true, with sexual abuse leading to impairment. This relationship seems even more pronounced in young girls with disabilities, and increases with increased severity of the abuse. Studies have found that various forms of sexual abuse are associated with increased odds of child functional impairment (Afifi, Taillieu, Kristene, Katz, Tonmyr & Sareen, 2015), increased prevalence and severity of depression, ill-health and substance use (Brunnberg, Boström & Berglund, 2012; Mitra, Mouradian & McKenna, 2013), increased general levels of mental health problems (Kvam & Loeb, 2010; Mitra, Mouradian & McKenna, 2013), suicidal attempts, stomach ache, dizziness, sleep problems, well being at home and bullying behaviours (Mansbach-Kleinfeld, Ifrah, Apter & Farbstein, 2015), increased levels of Post Traumatic Stress Disorder (PTSD) (Shabalala & Jasson, 2011) and conduct disorder (Soylu, Alpaslan, Ayaz, Esenyel & Oruç, 2013).

Consequences of abuse often reach far beyond the individual exposed to the abuse. A study from Canada, for instance, reported that sexual abuse of children with developmental disabilities increased what was already a significant burden of care for the families, and further reinforced stigmatization, marginalization,

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and powerlessness (Stewart, 2012). The study further showed that the sexual abuse victims, their families and relevant professionals are ill-prepared to cope with the complexities of sexual abuse and intellectual disability. A significant barrier is the lack of communication and sharing of expertise between the various child-protection systems. As a result of this compartmentalization of expertise, a full understanding of the sexual abuse experience is not gained, and the response is inadequate (Stewart, 2009).

Sexual abuse is not always discovered and reported, and not given the attention it should. It has been argued that this is even more pronounced among young girls with disabilities. Zaviršek (2002) argues that this is part of a subtle and unintentional discrimination, reflecting a continuity of prejudices and hatred toward disabled children and adults in the private realm as well as in public care (Zaviršek, 2002).

4.5 Self-determination and control

As shown in previous sections, most young people with disabilities aspire to having relationships and being married, but they face several barriers to achieving sexual autonomy. Young people in general are dependent on and to some extent controlled by their parents/ guardians, teachers and/ or other authority figures in their lives. As children become youth and young people become adults, the dependence on and control by others is slowly diminished, as they learn to look after themselves and find their own autonomy. For most people sexual development and identity is an important part of adolescence and adulthood and of becoming an independent human being. Many young people and even adults with disabilities are dependent on help and assistance from a multitude of formal and informal carers within the family, community or through various care services throughout their lives. The severity of an impairment largely determines the level of dependence on others. This dependency on and control by others has been highlighted in the literature as barriers to healthy sexual development and autonomy for young people with disabilities.

Several studies have found that young people with disabilities, especially with learning/ developmental/ intellectual disabilities, are overprotected by their carers, and are subject to great degrees of control and supervision (Franklin & Smeaton, 2017; Healy, McGuire, Evans & Carley, 2009; Kef & Bos, 2006; Löfgren-Mårtenson, 2004; Maia, 2016; McConkey & Ryan, 2001; McKenzie & Swartz, 2011; Rohleder & Swartz, 2009; Wilkinson, Theodore & Raczka, 2015). Young people with intellectual disabilities in particular are often seen and treated as 'eternal children', underestimated, giving parents legitimacy for overprotection and control (Maia, 2016). This leads to lack of privacy and independence for these young people to explore romance and sexuality, and contributes to undermining their sexual development.

Parents, teachers and other caregivers find themselves in a squeeze between a human rights discourse recognising the need for sex education and the importance of people with disabilities leading sexual lives, and a discourse of needing to guide, control and sometimes restrict the sexual expression of youth with disabilities in order to protect them. They are painfully aware of the vulnerability for sexual abuse and exploitation faced by young people with disabilities, particularly young girls with disabilities, and preventing this becomes the main goal of sexual education and development strategies targeted at them (Pownall, Jahoda, Hastings & Kerr, 2011; Rohleder & Swartz, 2009; Rohleder, 2010; Wilkinson, Theodore & Raczka,

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2015). A study from Ireland found that staff in residential facilities for youth with intellectual disabilities admitted to putting unnecessary restrictions on the sexual development of the residents. This was done in the best interest of the youth, and stemmed largely from the insecurities and lack of knowledge in the staff of how to deal with issues around sexuality and sexual development. Only a few had received any training in dealing with these issues, but all the more training had been provided towards understanding the vulnerability of this particular group, which may result in over-emphasis in avoiding sexual abuse and thus put unnecessary restrictions on the sexual development of the youth (McConkey & Ryan, 2001). There is a general lack of guidance for parents and caregivers on how to deal with sexuality among youth with disabilities (Löfgren-Mårtenson, 2004; Rohleder & Swartz, 2009; Rohleder, 2010), as we have shown in the section about sexual education above.

However, some studies have revealed a positive relationship between parental overprotection, monitoring and control and decreased adolescent (with disabilities) sexual risk taking (Kef & Bos, 2006; Nappi, Thakral, Kapungu, Donenberg, DiClemente, Brown & Project STYLE Study Group, 2009). This suggest that greater parental involvement and supervision may be necessary conditions for the protective effect of high quality family sexual communication on adolescent sexual risk taking. Adolescents of parents that perceive themselves as consistent monitors and capable of open and comfortable discourse about sex are more likely to implement safe sex practices (Nappi, Thakral, Kapungu, Donenberg, DiClemente, Brown & Project STYLE Study Group, 2009). On the other hand, a relationship has also been found between parental overprotection and lower scores of self-esteem among blind adults in the Netherland (Kef & Bos, 2006).

Ironically, a recent study from the UK found that factors putting young people with learning disabilities at increased risk for sexual exploitation were overprotection, disempowerment, social isolation, lack of sexuality education and not recognising their sexual needs (Franklin & Smeaton, 2017). This indicates that some measures used by carers to prevent sexual abuse may in fact end up putting these individuals at increased risk for sexual abuse.

4.6 Alternative sexual identities

There is a scarcity of literature on young people with disabilities and alternative sexual identities, often referred to as lesbian, gay, bisexual and transgender (LGBT) identities. The very few studies identified in this review are from Western/ industrialised countries (Sweden and Canada), focussing on youth with intellectual disabilities.

In Sweden, homosexuality is rarely seen among youth with intellectual disabilities, but it is argued that alternative sexual identities are as common in this group as in any other population group. It is further argued that youth with intellectual disabilities experience several barriers to healthy development and expression of any preferred sexual identity. As shown in the chapter above, youth and adults with intellectual disabilities often spend most of their lives in controlled environments, where alternative sexual expression is made difficult, because staff and parents are primarily concerned with teaching the youth to be sexually and romantically appropriate, and thus heterosexual identity is the primary focus of sex education. Alternative expressions are often misunderstood to be misdirected expressions that need to be

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adjusted, rather than expressions of homosexuality or other sexual identities (Löfgren-Mårtenson, 2004; Löfgren-Mårtenson, 2009; Löfgren-Mårtenson, 2012).

A study among youth with intellectual disabilities who identified as LGBT in Canada found that participants reported limitations to their autonomy by authority figures. This resulted in behaviour that led to unsafe sexual practices. In the context of virtual prohibition of their sexual activity within their homes, LGBT youth labelled with intellectual disabilities resort to uncomfortable and risky physical and social spaces for romantic and sexual encounters. Consequences of this include less physical safety, reduced opportunity for healthy decision making, less privacy, and unprotected sex. Contrary to stereotypical assumptions, youth with intellectual disabilities are discovering and exploring their sexuality, but they experience more external controls over their autonomy than others their age (McClelland, Flicker, Nepveux, Nixon, Vo, Wilson, Marshall., Travers & Proudfoot, 2012).

5 Gaps in knowledge and suggestions for future research

There are studies to suggest that young people with disabilities are stigmatized and that this stigma has a negative impact on their self-esteem and sexuality. However, much of the research is cross-sectional and present self-report experience. There is little on the development of sexual identity and how sexual self-esteem may evolve through adolescence and in to adulthood. The emphasis in most research tends to be on the negative – problems and challenges – and rightly so. However, there is a general absence of research that takes a more positive focus – on positive experience of sexuality, and different ways of experiencing satisfying sexual mutuality. This is also reflected when it comes to sexual education, where the topics most frequently covered are 'negative' – sexual abstinence, preventing pregnancy and STIs, and sexual abuse – but there is much less taught on 'positive' topics, such as having a satisfying sexual life.

Regarding sexual and reproductive health education, research fairly well establishes that young people with disabilities are more excluded and have less access to information. Much less research has been conducted on various educational interventions and their effectiveness, and various tools and methods for imparting information. There is lack of consensus, policy and guidelines for how to deal with sexual and reproductive health matters for youth with disabilities in schools, and lack of policy and guidelines for considering and including disability in sexual and reproductive health care services. Research consistently highlight the need for training of parents, teachers, carers and young people with disabilities themselves on issues of sexuality, sexual health and sexual development, but there is need for research on what the content and format of such training could or should be.

There is little research on specific sexual difficulties or psychosexual problems. It may most likely be the case that this is looked at in terms of adults with disabilities. However, we know little about adolescent sexual experiences and the impact that possible impairment-related sexual difficulties (for example, impotence) may have on the development of a sexual identity and sexual self-esteem.

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While there is ample evidence to suggest that people with disabilities in general, and girls with disabilities particularly, are more vulnerable to sexual abuse and exploitation, there is an overall weakness in the evidence in that there is no consensus as to what is meant by disability (or the various types of disability) and what is meant by abuse (or the various types of abuse). The different ways in which these concepts are identified and studied means that we are not comparing similar items when we are comparing two studies that both investigate the relationship between disability and abuse. There is need for a more common consensus, development and use of validated tools to study and measure prevalence of sexual abuse among people with disabilities. Challenges and shortcomings related to definitions, screening and measurement have also been highlighted in several other literature reviews within the field of disability and sexuality (Banks, Zuurmond, Ferrand & Kuper, 2015; Govindshenoy & Spencer, 2007; Jones, Bellis, Wood, Hughes, McCoy, Eckley, Bates G, Mikton & Shakespeare, 2017; Sequeira & Hollins, 2003; Wissink, van Vugt, Moonen, Stams & Hendriks, 2015). There is also not much in the literature on interventions to reduce the risk for abuse and victimization, to prevent abuse and to treat and assist disabled victims of abuse.

There is a major lack of evidence regarding disability and alternative sexual identities. The very few studies that were identified are from Western/ industrialised countries where there is generally higher tolerance for alternative sexual identities. It is likely that studies from other parts of the world, where acceptance and tolerance is lower, would highlight other, different or increased challenges.

The under-representation of research from many of the low- and middle-income countries of the world is a concern, given that the majority of the world's population of people with disabilities live in low and middle-income countries. Furthermore, a majority of the research in this field focuses on people with intellectual/ developmental/ learning disabilities, and there is need for more research on other disabilities. There is also substantially less research on girls and young women with visual disabilities compared to other disability categories.

It may be that specific issues and concerns related to girls and young women with disabilities are not looked at or are overlooked because many studies include both genders and refer to "people with disabilities" generally – also majority of studies may come from countries that have more attention to sexual and reproductive health rights of people with disabilities. In some regions of the world where such rights are less acknowledged, the plight of girls and young women with disabilities may be particularly dire, given the suggestion that girls with disabilities are less valued, and more likely to be abused. We need to know much more about girls and young women specifically (rather than people with disabilities as a homogenous group). Where specific issues for girls with disabilities are addressed they tend to be on sexual abuse, or the sexual hygiene (menstruation) of girls with intellectual disabilities, or the prevention of pregnancy. Far less attention is given to positive aspects of sexuality of young women with disabilities.

In many of the areas highlighted in this report, there is adequate knowledge of what the problems are, but a lack of knowledge about how to solve them. There is need for development of research-based interventions, evaluated for their feasibility, appropriateness and effectiveness. Future research and interventions should take on a human rights based approach to the sexuality of people with disabilities.

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7 Appendices

Appendix 1: Summary Table of Research Papers Reviewed Appendix 2: Summary Table of Review Papers Included

APPENDIX 1: SUMMARY TABLE OF RESEARCH PAPERS REVIEWED

| Authors | Year | Region | Population sample | Aim of study | Type of study | Main findings | Strengths & limitations |
|--|------|---------|---|---|---|--|--|
| Addlakha, R | 2007 | India | 2 men and 2 women with visual and locomotor disability. One woman is 19 years old. The other participants are over 20 | Intends to explore and discusses notions of sexual identity and gender among urban Indian youth with visual and locomotor disabilities. It aims to highlight key issues in an under-research area | Qualitative case studies | The case studies of the women suggest that the lower maritable "marketability" of the women (because of their disability) is compensated through employment and her economic self-sufficiency. Meanwhile their sexuality and sexual aspirations remain unrecognised. | The case studies provide a rich narrative of the participants' subjective experience, but it tends to be quite descriptive. The very small sample size makes it ungeneralizable. |
| Aderemi T.J., Pillay B.J. | 2013 | Nigeria | Indigenously Yoruba adolescents in south-west Nigeria. 300 (41% female) adolescents with mild/moderate intellectual disabilities and 300 non-disabled adolescents (51.3% female), ages 12-19 (mean age 16.3) recruited through various schools. | The study aimed to investigate and compare the sexual practices among a group of non-disabled adolescents and among a group of adolescents with intellectual disabilities, so as to identify factors associated with sexual abstinence behaviours. | A comparative cross-sectional survey design. | Higher rate of sexual abstinence among non-disabled adolescents. Fewer adolescents with disabilities reported never having had sex (73.7%) than non-disabled adolescents (84%). Girls with ID almost 4x more likely to report history of rape than non-disabled girls. Adolescents with disabilities reported having much older sexual partners than non-disabled adolescents. Adolescents with disabilities had significantly lower level of HIV transmission knowledge than non-disabled adolescents. Sexually abstinent and sexually experienced adolescents in both groups reported similar low HIV risk perception. | Strengths are a large and representative sample, which can be generalised. Limitations is that it relies on self-reporting of past sexual behaviours. |
| Aderemi T.J., Pillay B.J., Esterhuizen T.M. | 2013 | Nigeria | Indigenously Yoruba adolescents in south-west Nigeria. 300 (41% female) adolescents with mild/moderate intellectual disabilities and 300 non-disabled adolescents (51.3% | To compare the HIV knowledge and sexual practices of adolescents with mild/ moderate intellectual disabilities and non- disabled adolescents. | Cross-sectional, comparative survey study using a structured questionnaire developed for the study | Higher proportion of adolescents with disabilities than non-disabled adolescents reported sexual experiences. Adolescents with disabilities were more likely to report risky sexual exposures (inconsistent condom use, rape). Non-disabled adolescents were more likely to report multiple sexual partners. Adolescents with disabilities had less access to HIV information sources and had lower levels of HIV knowledge, with females being at a | Strengths are a large and representative sample, which can be generalised. Limitations is that it relies on self-reporting of past sexual behaviours. |

| | | | female), ages 12-19 (mean age 16.3) recruited through various schools. | | | disadvantage. Adolescents with disabilities also reported more alcohol use. | |
|---|------|----------|--|--|--|--|---|
| Aderemi TJ, Mac-Seing M, Woreta SA, Mati KA. | 2014 | Ethiopia | 209 men and 203 women with disabilities (physical, intellectual, mental, speech and sensory) aged 15- 49 (mean age 30). | To investigate HIV testing prevalence and factors associated with use of VCT services among people with disabilities in Addis Ababa | Survey questionnaire based on Ethiopia Demographic and Health Survey, measuring determinants of VCT use | HIV testing prevalence was 53.2% (lower than general population), with no significant gender differences. Only 30.8% of sample had comprehensive HIV knowledge. Their HIV risk perception was low, and determined HIV testing. Comprehensive HIV knowledge easy transport to facilities and ages 25-39 was positively associated with using VCT services. Living with both parents was negatively associated - likely refers to youth. People with mental/intellectual disabilities less likely to use VCT | Strengths: heterogeneous disabilities. Limitations: small, non-representative sample (author's note); people with hearing disabilities less represented. Descriptive and no comparison to non- disabled (although lower than general pop stats) |
| Afifi Z.E.M., El-Lawindi M.I., Ahmed S.A., Basily W.W. | 2003 | Egypt | 555 adolescents. Ages 12-18 (mean age of 15.6 years). Approx. 25% reported having learning disabilities. 68 adolescents had physical disabilities. | To investigate the prevalence of child abuse (physical, emotional, sexual) in a rural community, to identify risk factors, and detect the consequences of abuse | Survey study with physical examinations | 36.6% overall prevalence of abuse found. Emotional abuse most prevalence, followed by physical abuse and sexual abuse (7%). Having a disability increased likelihood of abuse. Disability was a significant predictor of sexual abuse. | Strengths: Random sample which can be generalized. Limitations: ethical issue of measuring abuse? (No mention of interventions). |
| Afifi, T.O., Taillieu, T., Kristene C., Katz, L., Tonmyr, L., Sareen, J. | 2015 | Canada | Data from the Canadian Incidence Study of Reported Child Abuse and Neglect = 6163 children aged 15 years and younger. 49.1% female and 50.9% male. | To examine the distribution of child and household characteristics among child maltreatment types. To determine if a specific maltreatment type was associated with increased functional impairment. To determine which child | Statistical analysis of incidence data. | Physical abuse, sexual abuse and neglect associated with increased odds of child functional impairment | Strengths: national data. Limitations: cross sectional. Does not specifically look at pre-existing impairment and risk of abuse. |

| Agarwal U., Muralidhar S. | 2016 | India | 100 people (76 males and 24 females) with physical disabilities attending out and inpatient facilities at a tertiary care hospital in New Delhi. Ages from 15 | and household characteristics were associated with functional impairment. To conduct a situational analysis of the sexual and reproductive health issues of people with physical disabilities attending a tertiary care hospital. | Cross-sectional survey, and blood checks for STIs from 20 subjects | Contraception used by 33% of sample (most commonly condom use). 78% were aware of HIV. Various sexual and reproductive health problems reported. 35% of serum sample (N=20) tested prevalence of chlamydia. Only 10% of patients had received sexual counselling from their rehabilitation providers. Only 22% of women opted for regular gynaecology visits. | Limitations: small sample of females; small serum sample. |
|---|------|----------|---|--|--|--|--|
| Ahumuza S.E., Matovu J.K.B., Ddamulira J.B., Muhanguzi F.K. | 2014 | Uganda | 40 people with physical disabilities (20 men and 20 women) aged 18 and above. 5 females aged 18- 24. | To explore the challenges faced by people with physical disabilities in accessing sexual and reproductive health services in Kampala | Qualitative study involving interviews with people with physical disabilities and with key informants | For females, the main challenges faced in accessing services were: poor physical access (80%), negative attitudes of health workers (75), and (for less than 50%) long queues, long distance to travel, high cost of service, and untrained health workers. Reported negative attitudes from health workers towards women with physical disabilities included being criticised or "despised" for being pregnant. | Strengths: explores subjective experiences of people with physical disabilities. Limitations: small sample, few girls with disabilities. |
| Alemu T., Fantahun M. | 2011 | Ethiopia | 384 young people (ages and gender not stated in the abstract) | to assess the sexual and reproductive health of young people with disabilities in Addis Ababa | cross-sectional survey using structured questionnaire, plus focus group interviews | Total 174(45.3%) had ever had sex; 100(57.5%) and 74(42.5%) were males and females respectively. 73 (42.0%) had first sex experience between 15-19 years. Only 9.2% were married. Only 45.4% of the sexually experienced had used contraceptive during their first sexual encounter. Prevalence of unintended pregnancy was 62.5% and 50% of them have had an abortion. 58.6% of those who were sexually active had multiple sexual partners, 20.7% had a casual sex partner. The prevalence of ever having STI was 25.3%.Only 55.5% had good HIV | Limitations: no comparison group. ONLY ABSTRACT AVAILABLE |

| | | | | | | transmission knowledge, 33.1% had good STI knowledge and 51.8% had good HIV Prevention knowledge. Only 33.3% of respondents had utilized reproductive health services. Conclusion: Young People with Disability at great risk for sexual and reproductive health associated problems. Female young people with disability are the most disadvantaged. | |
|--|------|--------|--|---|---|---|--|
| Almond, L., Giles, S. | 2008 | UK | 51 young people with learning disabilities (21 Mild LD, 26 moderate LD and 4 severe LD), and 51 comparison group with no LD. Data was obtained from case files of a service for children and young people with LD | To compare between young people with learning disabilities and without regarding their perpetrator, victim and sexual abuse characteristics. | Statistical comparison of case record data | Perpetrators of sexual abuse within the sample tended to be male. Mean age for victims of sexual abuse was 9.8 years in LD sample (similar to non-disabled). Females more than 2x more likely to be victims than males (same with non-disabled sample), with majority of perpetrators being known to them. | Strengths: comparison group, matched to age and gender. |
| Alquati Bisol C, Sperb TM, Moreno- Black G. | 2008 | Brazil | Deaf and hearing youths aged 18-20 yrs | To describe the process of conducting focus groups with deaf and hearing youth on topic of HIV knowledge | Focus group study | Girls tended to communicate more and be more open with sharing personal information. Some of the deaf participants suggested that vocabulary used be made simpler. | Limitations: do not provide data on experiences, but provides some comparison of conducting focus groups with deaf and hearing participants. |
| Alriksson- Schmidt A.I., Armour B.S., Thibadeau J.K. | 2010 | USA | 7193 female adolescents (most aged 15-18). 12.5% reported having a physical disability or chronic health problem. | to investigate whether female adolescents with physical or chronic health disabilities were more likely to report sexual violence than non- disabled female adolescents | Cross-sectional survey. Data from national survey statistics | 10.8% of total sample reported having experienced sexual violence. Adolescent girls with disability/health problem were twice more likely to report sexual violence than non-disabled girls. | Strengths: national comparative sample. Limitations: cannot establish causality. Severity of disability not none. |
| Altundağ S., Çalbayram N.Ç. | 2016 | Turkey | 54 adolescent (ages 13-17yrs, mean age 15) females with | To assess the effectiveness of teaching menstrual | One group pre- and post-test study | Generally, menstruation is called "getting 'dirty' or 'sick'" in Turkey. Menstrual care | Limitations: case specific, not generalizable. |

| | | | intellectual disabilities. | care skills to adolescent females with intellectual disabilities by demonstrating on a dummy. | | skills improved significantly post intervention. | |
|--|------|-----|---|--|---|--|---|
| Anderson M.L., Leigh I.W. | 2011 | USA | 100 Deaf or hard- of-hearing females aged 18-25 yrs (mean age 20.6), who have had at least 1 relationships over the past year. 83% were straight. | To investigate the prevalence of reported intimate partner violence in a sample of Deaf female college students. | Questionnaire survey study | Participants experienced an average of 20.65 psychologically aggressive behaviours, an average 7.67 physical assaults, and on average 8.51 sexually coercive behaviours over the past year. When compared to published data from hearing adolescents, it indicated that Deaf female college students report almost 2 times the prevalence of intimate partner violence. | Limitations: Comparison sample not matched in the same study. Self-reported data |
| Antaki C., Richardson E., Stokoe E., Willott S. (a) | 2015 | UK | Police interview recordings of 19 identified cases involving a person with intellectual disability as alleged victims. Of the 19, 14 claimants were young woman, one was a girl under age 14. | To analyse actual police forensic interviews with people with intellectual disabilities who are alleged victims of sexual assault and rape, to observe how claimants respond to police questioning of their allegations. | Conversation analysis of police interviews | Complainants with intellectual disabilities were found to at times be able to rebut or resist damaging or negative implications and claims by police interviewers (e.g. that their account is inconsistent or implausible). At other times they were not, and as a result the cases could not go to court. Results indicate that guidelines for framing interview questions in a careful and accessible way to claimants with intellectual disabilities, and carefully analysing their responses, are not always being followed. | Strengths: provides data to observe how guidelines are practiced in real terms. Limitations: case study specific and so not generalizable. |
| Antaki C., Richardson E., Stokoe E., Willott S. (b) | 2015 | UK | Police interview recordings of 19 identified cases involving a person with intellectual disability as alleged victims. Of the 19, 14 claimants were young woman, one | To analyse actual police forensic interviews with people with intellectual disabilities who are alleged victims of sexual assault and rape, to observe how police respond to | Conversation analysis of police interviews | Police tend to respond to claimants distress in interviews in three broad ways: (1) minimal or no acknowledgement of distress; (2) acknowledging distress in terms of the claimant's difficulty with proceeding; and (3) rarely with explicit reference to the claimant's actual emotion. Police's expectations to conduct interviews in an impartial and non-suggestible manner | Strengths: provides data to observe how guidelines are practiced in real terms. Limitations: case study specific and so not generalizable. |

| | | | was a girl under age 14. | claimants' distress during interviews | | may prevent them from responding empathically to claimant's distress. | |
|---|------|---------|---|---|--|--|---|
| Aragão J.S., de França I.S.X., Coura A.S., Medeiros C.C.M., Enders B.C. | 2016 | Brazil | 98 males (n=57) and females (n=41) with physical disabilities aged 18- 59. | To analyse factors that enhance vulnerability to sexually transmitted infections in people with physical disabilities. | Quantitative, questionnaire- based study | 15.3% reported having had an STI. Having fewer partners and having good hygiene was perceived as being a protective factors. Participants with a congenital disability were 3.4 times more likely to have had an STI than people with an acquired disability. Older respondents were more likely to have had an STI | Limitations: self-report data. Few girls under age 19. No comparison group |
| Arias B, Ovejero A, Morentin R. | 2009 | Spain | 376 people with mild intellectual disabilities aged 18 and older. Approximately equal number of males and females | To investigate couple relations and perception of love in people with Intellectual disabilities, and its relation to emotional wellbeing. | Quantitative, questionnaire- based study | There was a positive perception of couple relations, appraisal of love, and satisfaction, which positively affects emotional wellbeing. Similar to non-disabled population. | Self-report data and possibility of respondent positive bias noted by authors |
| Arulogun Dr. O.S., Titiloye M.A., Oyewole E.O., Nwaorgu O.G.B., Afolabi N.B. | 2012 | Nigeria | 167 deaf girls aged 11-24 (mean age 17.5). | To investigate the prevalence of abuse among women with hearing disabilities in Nigeria | descriptive cross-sectional survey | 146 (87.4%) of respondents reported ever having experienced abuse - mental/psychological (34.2%), bullying (24.7%), physical (22.6%) and sexual (18.5%). Teachers, fathers and neighbours were the main perpetrators. Those out of school were 1.2 times more likely to experience violence than those in school. | Strengths: Large sample. Limitations: no comparison group |
| Arulogun O.S., Titiloye M.A., Afolabi N.B., Oyewole O.E., Nwaorgu O.G. | 2013 | Nigeria | 167 women with hearing disabilities ages 11-25 (mean age 17.5). | To explore the experiences of women with hearing disabilities in accessing reproductive health services | descriptive cross-sectional survey | 158 respondents (94.6%) had ever visited a health facility for a reproductive health problem. Of these 60.1% visited government facilities. 163 respondents went with someone (most usually parents) to support them. Reasons for the visit included: pregnancy test (29.2%), contraception (26.2%), treating STIs (6.2%) and termination of pregnancy (4.6%). Communication with help of accompanying persons was most common (32.9%), followed by writing (27.2%). 6.3% were not able to communicate at all with service | Strengths: Large sample. Limitations: no comparison group |

| | | | | | | provider. 41.1% reported not being able to make themselves understood. 17.1% did not understand what the provider had said. 41.8% had missed their turn because they had not heard their name been called. Most were attended to in the company of the accompanying persons. 53.2% were concerned about confidentiality. Only 40.5% reported having received the information and service they wanted 17.1% reported feeling poorly treated by health provider. Main barriers to access were communication problems (40.5%), not findings someone to accompany them (24.3%), cost (10.8%) and negative attitude of staff (6.8%). | |
|--|------|-----|---|--|---|--|---|
| Ballan, M | 2012 | USA | 18 parents of children ages 6-13. Only one child was female | to explore communication about sexuality between parents and children diagnosed with autism. | Qualitative - interviews with parents | Parents felt that their child's sexual behaviours were stigmatized and feared. Most felt anxious about communicating with their child about sexuality, and cited their child's perceived ability to comprehend as a barrier. Some perceived their child as behaviourally immature and too young to talk to about sexuality. Parents also worried about their child overgeneralizing information about sexuality if taught about it. Topics most frequently touched on were sexual abuse prevention and personal hygiene. Most were concerned about sexual abuse. Most parents could not envisage their child with a future partner. | Limitation: Only one female child |
| Balogh, R., Bretherton, K., Whibley, S., Berney, T., Graham, S., Richold, | 2001 | UK | 43 psychiatric in- patients with intellectual disabilities ages 9- 21. 44% had mild and 37%) had | To investigate the occurrence of victimization and perpetration of sexual abuse among psychiatric in-patients | Quantitative - retrospective case note review. | 30 of patients were referred specifically for sexual abuse problems while it emerged during admission for the remainder. 37 cases were victimization 22 cases were perpetrators. 46% (21 cases) of the study group were female victims and 12% (5 | Based on case note data rather than self-report |

| P., Worsley, C., Firth, H. | | | moderate intellectual disabilities. | with intellectual disabilities. | | cases) were female perpetrators (all of whom were also victims). Greatest proportion of cases were in age 13-18yrs. More females had suffered penetrative sexual abuse. Abuse most frequently occurred within the immediate or extended family. | |
|---|------|-----|---|---|---|--|--|
| Barnard- Brak L., Schmidt M., Chesnut S., Wei T., Richman D. | 2014 | USA | 9230 students with disabilities, of whom 5070 students with intellectual disabilities. Of those with ID, 55.3% male; 32% female; 12.7% gender not reported; 63.2% were White. Ages 14-18. | To identify variables that predicted whether students with intellectual disability received sex education in public schools | Quantitative - analysis of data from national survey of schools in the USA | 43% of all 9230 students with disabilities received sex education. Individuals without ID were more likely to receive sex education that students with mild ID, and significantly more likely than students with moderate to profound ID. Results suggest that teachers may be making judgements about whether students with ID would benefit from receiving sex education. For students with ID expressive communication and social skills predicted receiving sex education | Strengths: Large national sample. Limitations: reporting is confusing (sample are all disabled, but focusing on ID) |
| Bat-Chava, Y., Martin, D., Kosciw, J. G. | 2005 | USA | 134 Deaf and hard- of-hearing ages 15- 76 (mean age 34). 55.2% were female. 52.6% white. 62.6% heterosexual. 24 were ages 15-21. | To investigate level of HIV knowledge and barriers to HIV education and prevention among deaf and hard-of-hearing people in USA | Qualitative - individual and focus group interviews | Level of HIV transmission and prevention knowledge was low among Deaf participants (there were regional differences), with satisfactory level of HIV knowledge among hard-of-hearing participants. Adolescents had good levels of HIV knowledge as they received education at school (but level of knowledge was variable). Relatively few had tested for HIV. Most common barriers to accessing HIV prevention and care was communication difficulties with health care professionals. | Strengths: compares between severity of hearing disability and adolescents/adults. Small sample size. |
| Bell D.M., Cameron L. | 2003 | UK | Young woman with severe learning disability (age not reported) | To describe the use of a method of communication (Talking Mats) to assess sexual knowledge of a person | Individual case study | The alternative method of communication was found to be helpful in communicating and assessing sexual health knowledge. | |

| | | | | with severe learning disability | | | |
|---|------|--------|--|---|--|---|--|
| Bezerra CP, Pagliuca LM. | 2010 | Brazil | Five adolescent females with visual disabilities aged 12- 17. | to explore the experience of puberty of adolescents with visual disabilities. | Qualitative interview study | Girls talked to older sister or friends about sexuality, not their parents. Few obtained sexuality education from their parents, when education was given, it was about preventing pregnancy. Participants were sexually curious (similar to non-disabled) | Limitations: very small sample size and very descriptive data. |
| Bilge A., Çeber E., Demirelöz M., Baykal Akmeşe Z. | 2013 | Turkey | 113 Parents of children with developmental disabilities | To determine the level of sexual and reproductive health and disability knowledge of parents of children with developmental disability, to provide training and determine its effectiveness. | pre- and post- intervention questionnaire study | Most of the parents (60.2%) believed they could not cope with their children's SRH, and were highly affected by their children's SRH experiences. Almost half (47.9%) considered receiving counselling. Those who considered receiving counselling had higher level of knowledge than parents who did not consider receiving counselling. The mean knowledge score of the parents increased after the training. | ONLY ABSTRACT AVAILABLE |
| Bisol C.A., Sperb T.M., Brewer T.H., Kato S.K., Shor-Posner G. | 2008 | Brazil | 42 deaf students (21 girls) and 50 hearing students aged 15-21 years. | To investigate the level of HIV knowledge among Deaf students in comparison to hearing students | Quantitative - computer assisted self- administered questionnaire | Level of HIV knowledge was significantly higher for hearing students than Deaf students. Only 47% of deaf students were able to correctly answer at least 7 out of 16 questions, while all hearing students answered at least 8 correctly. Hearing students were more sexually active, but deaf youths became sexually active at slightly younger age (14.5 years). 31% of deaf students (6 boys and 7 girls) reported a history of sexual abuse, compared to 2% of hearing students. No differences were found in number of sexual partners or pattern of condom use. | Strengths: includes a comparison group. Limitations: small sample |
| Blanchett, W.J. | 2000 | USA | 88 (49 female) College students with learning disabilities ages 18- 25 (mean age 21). 82% were white. | To explore HIV risk behaviour and access to HIV prevention education among young adults with learning disabilities. | Mixed methods: Questionnaire plus follow-up interviews with sub-sample of 10. | Students with LD equally engage in sexual activity as students with no LD. Many practice unsafe sex, but only 60% of those who were sexually active perceived themselves to be at some risk. The majority had received HIV education at high school. | Limitations: college students so mild level of disability - not generalizable. |

| Blum, R.W., Kelly, A., Ireland, M. | 2001 | USA | Six females (and 4 males) took part in interviews. 4035 youth with emotional disabilities (61.8% female; mean age 16.4); 1301 youth with learning disabilities (35.9% female; mean age 16.1), and 167 youth with mobility impairment (47.5% female; mean age 16.5). 15689 comparison group (49.2% female, mean age 16.1) | To identify health risk (suicide attempts; sexual abuse; regular smoker; alcohol and marijuana use) and protective factors of young people with disabilities (mobility, learning and emotional disabilities) relative to a comparison group | Quantitative. Survey data from a national school survey | Youth with disabilities were more involved in health risks than non-disabled peers, and had fewer protective factors. Those with emotional disabilities reported 6x more likely to attempt suicide than peers. Those with LD and those with mobility impairments were 3x more likely to report suicide attempts. Youth with disabilities more likely to report sexual abuse than peers. Welfare status a significant risk factor for sexual abuse for disabled youth. Family connectedness was a significant protective factor | Strengths: large national sample. Limitations: only sexual focus is on reported sexual abuse. |
|---|------|--------|--|---|--|--|--|
| Bottoms B.L., Nysse- Carris K.L., Harris T., Tyda K. | 2003 | USA | 160 undergraduate psychology students | To investigate mock jurors perception of a adolescent sexual abuse victims credibility as a function of their being portrayed as having an intellectual disability | Experimental study | When the victim was portrayed as having an intellectual disability, mock jurors considered their allegations as more credible and the defendant as less credible. . They rated the victim as more honest and less likely to have fabricated the allegation. Mock jurors were more confident in finding the defendant guilty when victim portrayed as having an intellectual disability. | Strengths: experimental design. Limitations: use of psychology students; not a "real world" study |
| Brownlie E.B., Jabbar A., Beitchman J., Vida R., Atkinson L. | 2007 | Canada | 142 children (52 girls) with diagnosed language impairment, followed from age 5 to age 25. 95% were white. !42 children in control group matched for age and gender. | To examine the prevalence of sexual assault by age 25 among participants with language impairment and comparison group, and the psychological outcomes of sexual victimization | Quantitative. 20-year longitudinal study | Women with language impairments (45.5%) were most likely to have experienced sexual assault by age 25. Mean age of first sexual assault were 10.57 years. Of the 25 women who reported sexual assault, 32% met criteria for current psychiatric disorder (compared to 4.5% of women who did not report sexual assault). Language impairment may hinder women from talking about their experiences. | Strengths: good sample size and longitudinal study |

| Brunnberg | 2012 | Sweden | 112 (44 women) with language impairment participated at follow up. 4748 adolescents | To compare incidence | Cross-sectional | 1652 girls reported having made their | Strengths: large national |
|---|------|--------|--|--|--|--|---|
| E., Boström M.L., Berglund M. | | | age 17/18, of which 2377 were girls. 643 (270 girls) reported one disability; 160 (60 girls) reported multiple disabilities, 3945 (2047 girls) were non-disabled. | of force on first sexual experience reported by students with disabilities compared to non-disabled students, and differences in mental health, substance abuse and educational performance | national survey study | sexual debut. Of these, 245 of 330 girls with disabilities. Of these 13 girls with disabilities reported force at sexual debut. Force at sexual debut is most frequent for girls with multiple disabilities (10.4%), followed by the one disability group (4%) and non- disabled (1.6%). All more frequent than in boy groups. Girls who reported force at sexual debut more likely to report depression, ill-health and substance use. | sample. Limitations: type of disability not specified. |
| Brunnberg E., Boström M.L., Berglund M. | 2009 | Sweden | 5323 15/16 year old adolescents. 281 girls with one disability (294 boys), 69 girls with multiple disabilities (97 boys) 2390 non- disabled girls; (2189 non-disabled boys). | To compare the sexual debut of 15/16 year old girls and boys with and without disabilities | cross sectional national survey | Adolescents with disabilities reported higher rate of sexual debut than non- disabled adolescents. Girls with several disabilities (59%) reported sexual debut more significantly than girls without a disability (34%). | Strengths: Large national sample. Limitations: limited data about sexuality |
| Bucchianeri M.M., Gower A.L., McMorris B.J., Eisenberg M.E. | 2016 | USA | 162034 adolescents (49.6% girls) | To investigate prevalence of prejudiced based harassment (including on the basis of disability status) among adolescents | Quantitative. State-wide cross-sectional survey | 11,4% of girls reported a physical disability, of whom 7.6% reported disability based harassment. 22.5% of girls reported mental health/emotional disability, of whom 14.4% reported disability-based harassment. 4.2% of girls reported both physical and emotional disabilities, of whom 23.5% reported disability-based harassment | large sample, but limited detail on nature of harassment |
| Burke, L., Kalpakjian, C.Z., Smith, Y.R., Quint, E.H. | 2010 | USA | 44 adolescent females (age less than 21); 13 with Down Syndrome, 14 with autism, and | To identify and compare the gynaecological issues of adolescent girls with Down Syndrome, | Quantitative. Review of medical records | Mean age at presentation to the clinic was 15 years. Age of menarche was 12.5 years. Age of onset of menarche for girls with cerebral palsy was later. Most frequent complain was irregular bleeding and | Strengths: medical data, and different types of disabilities. Limitations: Small sample |

| | | | 17 with cerebral palsy. | autism and cerebral palsy at a gynaecological clinical for women with developmental disabilities | | mood/behavioural changes, and menstrual pain. Girls with autism significantly more likely to present with behavioural issues. | |
|--|------|-----------------|---|---|---|---|---|
| Caldas S.J., Bensy M.L. | 2014 | USA | 352 respondents (parent or carer, or victim (15.8%)). Target population are children/ students with developmental and cognitive disabilities. 46.6% were female. 79.3% were white | To examine the profile of a large national sample of students with disabilities allegedly sexually maltreated at school. | Quantitative. Web-based survey questionnaire, designed for the purposes of this study | 70% reported experiencing at least one form of sexual maltreatment. Maltreatment most frequently occurred at ages 14-17; 52.6% occurred between ages of 6 and 13. 55.1% of those reported maltreatment had severe disability. Most frequently reported was verbal sexual harassment (68.5%). 30% reported rape. In 30.3% of cases the perpetrator was reported as being teaching staff. | Limitations: sampling those who have been mistreated. Responders are mostly second-hand reporters. Online survey cannot ensure accuracy of suitability of responders. |
| Cederborg AC., Danielsson H., La Rooy D., Lamb M.E. | 2009 | Sweden | Cases of 33 children and youth with intellectual disabilities (25 females). Ages 5 to 23 (mean age 13) | To examine the effects of repeating questions and making prompts in interviews investigating sexual abuse of children with intellectual disabilities. | Mixed methods - analysis of case files and transcripts of interviews | Six percent of questions were repeated, and interviewees changed their answers 40% of the time. Interviewees were more likely to change their response the greater number of times the question was repeated. This raises doubts about their reports, as these repeating of questions is potentially contaminating. | Strengths: analysis of "real world" data. Limitations: small sample size |
| Chappell P. | 2014 | South Africa | 22 Zuku-speaking youth ages 15-20 with physical and visual disabilities. 11 were female 96 with visual disability and 3 with physical disability). | To explore how a group of Zulu-speaking youth with physical and visual disabilities understand love, relationships and their sexual identity | Qualitative - focus group and individual interviews. | Most participants took the notion of love seriously, with females emphasising romantic love, trust and commitment. However, some women were willing to accept a partner who may cheat on them. Men were perceived as responsible for initiating relationships. Many saw dating non-disabled partners as a means of reducing stigma and discrimination. As with non-disabled youth reported in other studies participants reported similar gendered conceptions of love and relationships. | Strengths: explored meaning of relationships among youth; design was participatory. Limitations: small sample size |

| Chappell, P | 2016 | South Africa | 22 Zulu-speaking youth ages 15-20 with physical and visual disabilities. 11 were female 96 with visual disability and 3 with physical disability). | How youth with disabilities experience communications with their parent/carer about sexuality and HIV | Qualitative - focus group and individual interviews. | Most participants reported great difficulty in talking to their parent/carer about matters of sexuality. They feel parents perceive them as to young to understand; while they perceived their parents as too old and lacking in knowledge about youth and sexuality. They reported a culture of sexual secrecy and respect. Participants reported developing their own secret language and use of secret words with their peers and siblings in which they can talk about sexuality matters (e.g. "OMO" for "HIV"). | Strengths: explored personal experience of youth; design was participatory. Limitations: small sample size |
|----------------------------------|------|-----------------|--|---|---|--|---|
| Cheng M.M., Udry J.Richard | 2002 | USA | 1153 adolescents (mean age 15/16) with reported physical disabilities. 17695 non- disabled. | To examine differences in sexual behaviour between physically disabled and non- disabled adolescents | Quantitative. Data from a national longitudinal study on adolescent health. | Adolescents with disabilities are slower in pubertal development and report being more socially isolated. Yet they report being as sexually experienced as their non- disabled peers. They have similar exposure to sex education than non-disabled peers. Severely disabled girls (and boys) are less sure of their sexual preferences. Adolescent girls with disabilities are more likely to report forced sex. | Strengths: large national sample. Limitations: limited details about disability and sexuality. |
| Cheng, M.M., Udry, J.R. | 2002 | USA | Adolescents with mental disabilities | To examine adolescents' with mental disabilities' knowledge of sex and birth control, and whether their parents discuss these matters with them at home. | Quantitative. Data from a national longitudinal study on adolescent health. | Adolescents with mental disabilities have little exposure to sex education in school, and their parents tend not to discuss sex, birth control, and pregnancy with them. Their 'knowledge' is largely incorrect. Parents are mostly unaware of their child's sexual activity | ONLY ABSTRACT AVAILABLE |
| Clatos, K., Asare, M. | 2016 | USA | 15 parents of children aged 10-25 with various (mostly developmental) disabilities (33% of | To test the effectiveness of a sexuality education programme for parents of children with disabilities | Quantitative - pre- and post- intervention design | Overall there was a positive change in participant's beliefs about sexuality, sexual communication, knowledge of sex education, and self-efficacy in educating their children post-intervention. Before intervention, many believed their child was | Limitations: small sample size and intervention specific. |

| | | | the children were female) | | | not interested in sex or did not need sex education. | |
|---|------|-----------------|---|---|---|--|--|
| Cooke, P., Standen, P. J | 2002 | UK | 73 chairs of Area Child Protection Committees in the UK | To investigate current practices of Child Protection Committees in recording the abuse of children with disabilities | Mixed methods - survey and interviews with key workers of 8 children | 33% of authorities had specific guidelines for the protection of children with disabilities. 51% recorded the fact that the abused child had a disability. Only 45% gave any details of type of disability. However, only 14% could give actual figures. Having specific guidelines tended to correspond with better reporting. Analysis of schedules completed over a 1-year period showed that disabled children who were conferenced for abuse were less likely to be put on the child protection register than comparison non-disabled children. Interview data results showed that children with disabilities did not have equal opportunities with regards to services when compared with non-disabled children. Insufficient training was sighted as a factor. | Strengths: focus on actual practice. Limitations: small sample |
| Czapla, K., Otrębski, W. | 2014 | Poland | 61 people (50.8% females) with cerebral palsy ages 15-25. | To investigate the self- esteem levels and sexual needs of young people with cerebral palsy. | Quantitative - questionnaires | 64% had low self-esteem and sexual needs. They were unconfident in their sexual skills and abilities and their role as a sexual partner. | Limitations: small sample. No comparison group. Descriptive stats |
| Davies E.A., Jones A.C. | 2013 | UK | 138 cases of recorded sexual abuse | To identify possible risk factors predisposing children to sexual abuse | Quantitative - records of children involved in sexual abuse allegations over a year | Greatest risk factor was alcohol or drug use (38.4%) psychiatric disability (11.6%), learning disability (6.5%) and physical disability (4.3%) were also potential risk factors for children aged 7-12. Most perpetrators were known to the victim. Ethnic minorities may be under-reported | Strengths: use of actual case data. Information about disability and abuse is correlational and descriptive |
| Dawood, N., Bhagwanjee, A., Govender, K., Chohan, E. | 2006 | South Africa | 90 adolescents (ages 14-16) with mild mental retardation. 26% were female | To investigate HIV knowledge, attitudes and sexual practices among adolescents with mild mental retardation | Quantitative - survey questionnaire | Results indicate participants had a high exposure to HIV information, but indicated critical gaps in knowledge and understanding. Participants had low reported levels of self-efficacy in sexual | Limitations: sample is from one school |

| | | | | | | negotiation. 14% reported being sexually active, with low condom use | |
|---|------|------------------------|--|---|--|---|---|
| de Andrade V., Baloyi B. | 2011 | South Africa | 7 deaf adolescents aged 16-21. | To explore deaf adolescents concerns regarding sources of HIV knowledge and their level of HIV knowledge | Qualitative - semi-structured interviews | Teachers were cited as the main source of information about HIV but participants did not always understand them. They felt the information they had was inadequate. | Limitations: very small sample size. |
| de Andrade, V., Baloyi, B. | 2010 | South Africa | 7 deaf adolescents aged 16-21. | To explore level of HIV knowledge among a sample of deaf adolescents | Qualitative - semi-structured interviews | Participants had basic knowledge about HIV with misconceptions about transmission and the nature of HIV | Limitations: very small sample size. |
| de Reus L., Hanass- Hancock J., Henken S., van Brakel W. | 2015 | South Africa | 47 teachers at special education schools | To explore the challenges faced by teachers in delivering sexuality and HIV education to learners with intellectual, hearing and visual disabilities | Qualitative - focus groups | Teachers tended to focus on topics of bodily development, personal hygiene and sexual abstinence, and neglected topics of sexual behaviour. This was reported as due to feeling unskilled in knowing how to deliver such education. They also reported that sexual abuse was a major concern. Teachers also had the challenge of having learners of different ages and different severities of disabilities in their class at the same time. They reported needing more training and teaching materials. | Strengths: good sample size dealing with different disabilities. Limitations: context specific |
| Dekker L.P., Hartman C.A., Van Der Vegt E.J.M., Verhulst F.C., Van Oort F.V.A., Greaves- Lord K. | 2015 | The Netherla nds | 1687 adolescents aged 10-12 years at T1 and 12-15yrs at T2. | To investigate the longitudinal relationship between childhood autistic traits and parent- reported sexual problems in adolescence | Longitudinal survey study | Higher levels of autistic traits in childhood significantly predicted psychosexual problems in early adolescence | Population sample, but unclear proportion with disabilities. |
| Devries K.M., Kyegombe N., | 2014 | Uganda | 3706 children and young adolescents aged 11-14 (8.8% of boys and 7.6% | To explore the prevalence, patterns and risk factors for physical, sexual and | Quantitative analysis - secondary analysis of | Prevalence of abuse for all children were high. Disabled girls reported slightly more physical (99.1% vs 94.6%) and significantly more sexual violence (23.6% vs 12.3%) than | Definition of violence was overly-inclusive. E.g. definition of physical violence included mild physical acts of |

| Zuurmond M., Parkes J., Child J.C., Walakira E.J., Naker D. | | | reported a disability). | emotional violence among disabled children in primary school | national survey data | non-disabled girls. Most violence occurred at school. | rough play which could perhaps be interpreted as violence (e.g. someone kicked you). |
|--|------|-----------------|--|---|--|---|---|
| Dickman B.J., Roux A.J. | 2005 | South Africa | 100 cases of complainants with learning disabilities. 92.6% were female. Age at time of abuse ranged 6 to 40 years (average 18.5 years) | To describe demographics of complainants of sexual assault cases over a 10 year period, and describe a project which aims to assist complainants | Quantitative. Analysis of case reports | 90% of charges were rape. Of 56 complainants over age of 16, 46% were able to consent, with 39% unable to consent (the remainder was not evaluated). 58% were found to be competent to testify. Perpetrator was known to victim in 89% of cases. Conviction rate was 28% (equivalent to within the general population) | Strengths: use of case data. Limitations: descriptive data |
| Donenberg GR, Wilson HW, Emerson E, Bryant FB. | 2002 | USA | 169 urban youth aged 12 to 20 (45% female) in psychiatric care. | To investigate whether perceived parental monitoring and permissiveness were linked to high-risk sexual behaviour | Quantitative - questionnaires | Overall high levels of sexual risk taking. Girls reported more risky sexual behaviours than boys. At high level of parental permissiveness, girls reported more sexual risk behaviours. | Limitations: self-report data. Other factors not considered |
| Duh, J | 2000 | Taiwan | 284 high school students. 104 with visual disabilities (50 girls). Ages 12 to 18. | To investigate the sexual knowledge of adolescents with visual impairments in Taiwan, compared to non- disabled peers. | Quantitative - survey questionnaire developed for this study | Adolescents with visual impairments had lower levels of sexual knowledge than non- disabled cohort. The earlier the onset of visual impairment the lower the level of knowledge. The higher the level of knowledge the less likely adolescents would report sexual assault. | Limitations: comparison between gender appears not reported |
| Dupras, A., Dionne, H. | 2014 | Canada | 10 parents of children (5 girls) with mild intellectual disabilities | To explore the training needs of a sample of parents of children with intellectual disability | Qualitative - focus groups | Parents were aware of their children sexual curiosity and interests. They were concerned about their vulnerability, and some felt their children did not follow sexual morals, and doubted their child's ability to control their sexual impulses. Parents expressed anxiety and fear in dealing with their child's sexuality and felt they had a lack of knowledge and skills. | Limitations: small sample |
| East L.J., Orchard T.R. | 2014 | Canada | 3 females and 1 male with physical | Exploring the development and | Qualitative interviews | Adolescents with physical disabilities face the same sexuality, identity and self-image | Limitations: very small sample |

| | | | disability ages 15- 20 | challenges associated with sexuality, self- image and identity of Canadian adolescents with physical disabilities | | challenges as non-disabled peers. However, many of these issues are reportedly ignored or overlooked by adults | |
|--|------|-----------|---|--|--|--|--|
| East, L.J., Orchard, T.R. | 2014 | Canada | 3 females and 1 male with physical disability ages 15- 20; 4 parents of children with physical disabilities aged 18-21; and 4 health professionals | To explore the experiences, challenges and barriers associated with sex education from the perspective of a sample of young people with physical disabilities, their parents and health professionals. | Qualitative - individual and group interviews | Youth reported a lack of sex education from health providers. Youth felt that stigma and misconceptions of others were barriers to accessing information. Parents and health professionals felt unprepared and misinformed and tended to deflect responsibility to other groups. | Strengths: exploring different perspectives. Limitations: very small sample |
| Eastgate G. | 2005 | Australia | 12 year old female with Down Syndrome | To illustrate key issues of consent and sexual and reproductive health for people with intellectual disability | Case Study | Education and advocacy is needed to protect the individual from abuse. May need assistance in simplifying information when needing to make reproductive health choices. | Limitations: case study and very descriptive |
| Eisenberg ME, Gower AL, McMorris BJ, Bucchianeri MM. | 2015 | USA | 122180 adolescents (49.8% females). Of females, 11.7% reported having a physical disability; 10.2% reported a mental health/ emotional disability, and 4.6% reported having both physical and mental health/ emotional disability | To investigate perpetration of bullying among vulnerable youth compared to non- vulnerable youth | Quantitative - state-wide survey study | Rates of bullying (physical and relational) were higher for girls in vulnerable groups. | Strengths: large sample. Limitations: limited data related to disability and nature of bullying |
| Elliott Smith R.A., Pick L.H. | 2015 | USA | 70 deaf female university students aged 18-40. 70% | To explore the prevalence of sexual assault among deaf | Quantitative - survey study | 69% of respondents reported experiencing at least one sexual assault during their lifetime (higher than general population | Limitations: university students. |

| | | | were younger than 26. The majority were ethnic minority students | female university students. | | average), most commonly coerced sex while too inebriated to consent and forced sex. | |
|---|------|------------------------|--|---|--|---|--|
| Esmail S, Darry K, Walter A, Knupp H. | 2010 | Canada | Total 32 participants - focus groups with: service providers, general public, people with visible disabilities, people with invisible disabilities. Aged 18 and over | To describe societal attitudes towards sexuality and disability, and differences in stigma between individuals with visible and invisible disabilities | Qualitative - focus groups | Stigma can lead to people with disabilities internalising concepts of asexuality, which impacts negatively on sexual self-concept, confidence, desire and ability to find a partner. | Limitations: small sample. Number and gender of disabled participants not reported |
| Euser S., Alink L.R.A., Tharner A., van Ijzendoorn M.H., Bakermans- Kranenburg M.J. | 2016 | The Netherla nds | 104 professionals working in care facilities for children with mild intellectual disability | To examine the prevalence of child sexual abuse in out-of- home care for children with mild intellectual disability compared to out-of-home care non- disabled children and children in the general population | Quantitative - analysis of registration forms | Prevalence estimate of 9.7 per 1000 children were victims of child sexual abuse. This is slightly higher than regular out-of- home care (3.5 in 1000) and the general population (0.8 in 1000). The majority of the victims (75%) were female. | Strengths: national sample. Limitations: second-hand reported data |
| Evans D.S., McGuire B.E., Healy E., Carley S.N. | 2009 | Ireland | 155 staff members and 153 family carers of people with intellectual disabilities under age 34 (mean 28). The service users included adolescents, but age range not reported. | To explore the attitudes of sexuality and disability of staff and family carers of people with intellectual disability | Mixed method questionnaire survey | Significantly more staff carers (53%) than family carers (29%) had ever discussed issues of sexuality with the service users with intellectual disability. More female family carers than male had discussed sexuality issues. A larger proportion of family carers (35% compared to 20%) reported feeling unconfident discussing sexuality issues. Staff carers were more likely than family carers to note environmental issues than service-user characteristics as barriers to sex education. Family carers showed a preference for platonic relationships and preferred low | Strengths: representative sample. Limitations: age and gender of service users not reported on. |

| | | | | | | levels of intimacy and privacy in the relationships of service users. Overall staff carers were more open to the sexuality of service users than family carers | |
|---|------|----|--|--|---|---|---|
| Ferguson A.P., McKinlay I.A., Hunt A. | 2002 | UK | 138 parents from Tuberous Sclerosis Association of children with severe learning disabilities (60 females, with median age 19.6years). And comparison group of young people with severe learning disabilities from other causes | To investigate the young person's personal ability to care for themselves, their social interaction (including sexuality) and parents' concerns. | Quantitative - postal survey study | The young people's reported lack of social awareness reportedly affected their sexual behaviour. Fewer young people with TS related intellectual disability were able to distinguish between the sexes, and they were more likely to be perceived as less able to manage an intimate relationship. Interest in sexual activity was reportedly lower. Fewer young people with TS ID had an understanding of sex than the comparison group. The comparison may have had greater opportunities for sex education. | Strengths: comparison between types of intellectual disability. |
| Finlay W.M.L., Rohleder P., Taylor N., Culfear H. | 2015 | UK | Teachers and young people (ages 16 to 19) with intellectual disabilities taking part on sex education classes | To examine the delivery of sexual health education classes to people with intellectual disabilities | Qualitative - conversation analysis of lessons, and interviews with teachers | Issues of miscomprehension by young people with disabilities occurs when teaching makes use of complex sentences, and use abstract concepts. Teachers report struggling to find ways of phrasing statements that can be understood by the young people. They often adopt the strategy of repeating information to aid comprehension. However, when incorrect answers are given, teachers prompt and 'search' for the correct answer, but it remains unclear whether the young person has effectively understood the question/concept or merely provided the perceived correct answer. Thus, learner and teacher jointly produce a superficially "correct" answer. | Strengths: use of "real world" data. Limitations: small sample |
| Firth H., Balogh R., Berney T., | 2001 | UK | 43 patients in a psychiatric service for children and | To assess the extent of PTSD in a sample of child and adolescent | Quantitative - analysis of case note data | 15 females and 6 males were victims only of sexual abuse. 5 females and 11 males were both victims and perpetrators. Only | Limitations: small sample from one service |

| Bretherton K., Graham S., Whibley S. | | | adolescents with intellectual disabilities ages 9 to 18. Not clear how many were female. | perpetrators and victims of sexual abuse, and the distinction in motivation of perpetrators | | one case of PTSD was found. Sexual abuse directed at younger victims was associated with the perpetrators earlier experience of multiple forms of abuse. | |
|---|------|-----|---|--|---|---|--|
| Franklin A., Smeaton E. | 2017 | UK | Services supporting young people (under age 25) with learning disabilities. Interviews with 34 key stakeholders. 27 young people with learning disabilities (ages 12 to 23; 20 female) | To examine the identification of, and support for young people with learning disabilities who had been sexually exploited. | Mixed methods - survey and interviews with staff | Young people at high risk of child sexual exploitation, due to over-protection, disempowerment, social isolation, lack of sexuality education, unrecognising their sexuality needs. There is also an overall failure of adults to notice and recognise sexual exploitation having occurred. Many young people with learning disabilities reportedly not referred to support services for child sexual exploitation. Reported gaps in national and local policy and implementation of guidelines. | Strengths: Triangulation of data and methods. Data collected from different perspectives/ samples. |
| Gabriel K.O.S., Getch Y.Q. | 2001 | USA | 71 educators from various schools, who are teaching children who are deaf | To explore whether schools for the deaf were supporting parents in communicating with their children about sexuality, and whether parents are involved in sex education within the school | Quantitative - questionnaire survey | Sex education tends to be provided as part of an existing class, and only taught as a separate subject for 18.6% of respondents. Sexuality education was mostly delivered in small groups. Most curricula covered all topics, although "a few" educators reported that topics around contraception, sexually transmitted diseases, sexual identity and sexual assault or rape was discouraged or not allowed. 21.7% of respondents indicated that parents are involved in sexuality education. | Limitations: small sample and quantitative data are descriptive |
| Goldstein M.F., Eckhardt E.A., Joyner- Creamer P., Berry R., Paradise H., Cleland C.M. | 2010 | USA | 700 deaf students (70% deaf and 30% hard-of-hearing) recruited through 15 high schools for the deaf. 47% were female. Different ethnicities, | To develop and test a computerized self- administered HIV knowledge questionnaire using American Sign Language to assess | Quantitative - National survey study | The majority of respondents indicated that they got most of their HIV information from school (70%), with other sources being internet and print media (56%), friends (55%), television (44%), and family (44%). Students had a low level of HIV knowledge. This varied across schools, indicating the effects of the school environment on | Strengths: large sample size. Limitations: participation of younger students' dependent of parent's consent (there were fewer younger children). |

| Groce, N.E., Yousafzai, A.K., van der Maas, F. | 2007 | Nigeria | different sexual orientations 50 deaf and hard- of-hearing adolescents and young adults (52% female), and a comparison group of 50 hearing adolescents and young adults | level of HIV knowledge among deaf students To compare HIV knowledge among deaf and hearing individuals to assess access to HIV education in Nigeria | Quantitative - survey questionnaire | knowledge. The amount and content of HIV education in schools varied greatly. Deaf and hard-of-hearing participants had lower levels of HIV transmission knowledge, but similar levels of HIV prevention knowledge. Deaf and hard-of-hearing respondents had significantly less access to all types of sources of HIV information | Strengths: comparison group. Limitations: small sample size |
|---|------|---------|---|---|---|---|--|
| Grossman S.F., Lundy M. | 2008 | USA | Victims of sexual abuse and assault from the records over a 6.5 year period of 32 rape crisis centres. Of these 1093 individuals (2.5%) were recorded as having at least one disability. Most of these (60.5%) had a developmental disability. Others included hearing disabilities, visual disabilities, visua | To compare the services provided to individuals with and without disabilities who were victims of sexual assault and abuse | Quantitative - data from case records | Approximately 85% of victims were female. Average age was 27.8 years with 28.5% being under age 18. 73.2% were white. 21.1% were adult survivors of incest or sexual assault. The most common location was at home (44%), followed by offenders home (20%), and 14% in a public place. The majority of offenders were known to the victim. Those with disabilities were more likely to be referred via social services. Non- disabled were more likely to self-refer. Victims with disabilities more likely to receive range of services. | Strengths: Large sample size. Limitations: comparison group represents a matched selection. Only in 1 state of USA |
| Gürol, A., Polat, S., Oran, T. | 2014 | Turkey | 9 mothers of children with intellectual disabilities (3 females) aged 7- 18yrs | To explore the views of mothers of children with intellectual disabilities about sexual education | Qualitative - interviews and focus groups | All mothers stated that they did not provide sexuality education, saying that this should be provided by schools, and that they should participate in these classes too. All felt that their children should be taught personal hygiene skills and moral behaviour. The mothers did not think that family planning was a necessary subject to be taught to their child, stating that their child could not and should not have sex. All watched over their children closely, seldom leaving them alone. | Limitations: small sample size. Severity of disability not reported. |
|--|------|--------|---|--|---|--|--|
| Gust D.A., Wang S.A., Grot J., Ransom R., Levine W.C. | 2003 | USA | 115 (out of 168) state residential facilities for people with intellectual/develo pmental disabilities | To obtain information about sexual behaviour policies in state residential facilities for people with intellectual/developme ntal disabilities | Quantitative - survey questionnaire | All had state laws against sexual abuse. 95% had written policies about sexual abuse; and written policies about HIV (77%), STDs (56%), and pregnancy (38%). 30% had written policies for all of these. 4% had none. 86% reported that staff were trained before starting work to recognise signs of sexual abuse. 65% reported that their female clients used contraception. 6 facilities reported at least one instance of STD in the past year. 110 cases of sexual abuse were reported (most perpetrators and victims were male). Most perpetrators were known to the victim. | Limitations: not a lot of details of service users. Data used is from pre 2000 |
| Hadley, W, Barker, D.H, Lescano, C.M, Stewart, A.J, Affleck, K., Donenberg, G, DiClemente, R., Brown,L.K | 2014 | USA | 893 adolescents (56% female) with psychiatric disabilities. | To investigate the association between sexual risk behaviour and psychiatric disability among adolescents | Quantitative - questionnaires | Psychiatric impairment was linked to personal and peer factors that have been previously linked to sexual risk behaviours. Among sexually active participants, sexual risk behaviours were associated with impairment and previous condom use. For non-active participants, psychiatric disability influenced self-efficacy and condom use norms. | Strengths: large sample size. Limitations: demonstrate correlations, not cause |

| Hanass- Hancock J. | 2009 | South Africa | 25 people with disabilities and their caregivers | to explore the intersection of disability and gender stereotyping and how this may increase vulnerability to HIV | Qualitative - interviews | Sexual abuse was ranked as the primary problem for women with disabilities (and ranked second least for men). Many reported being perceived as "sexually abnormal" (as either not sexual, or sexually disinhibited). Disability in Zulu culture is perceived as a curse, reducing their acceptance as a potential partner or spouse. Participants reported that young women with disabilities are targeted in a sexual way because they are perceived as virgins and thus "clean" (of HIV). Sexuality is highly determined by gender norms, with a man needing to be 'active' and a woman 'submissive'. People with physical and intellectual disabilities are particularly disadvantaged as they are perceived to not fill traditional gendered roles. Women who are deaf may be sought after as an ideal 'submissive' spouse. People who cannot talk or are deaf are reported to be targets for sexual abuse, and have difficulties reporting rape. Most (19/25) reported not having received sex education or their parents would not educate about sexuality. | Limitations: age and gender, and type of disability of participants not reported |
|--|------|-----------------|--|---|--|---|--|
| Harris J.E., Colantonio A., Bushnik T., Constantinid ou F., Dawson D., Goldin- Lauretta Y., Swaine B., Warren J. | 2012 | Canada | 20 key stakeholders from 5 countries | To assess priority issues for girl's and women's health and quality of life following brain injury | Qualitative - findings from a workshop | There are significant gaps in community based service provisions. Clinicians provide general interventions that are not always focused on individual concerns (incl. sexuality and stigma). Concerns around prolonged amenorrhea. Clinical concerns included challenges in counselling women with brain injury about reproduction, possibly missing signs of sexual abuse because signs may be similar to brain injury sequelae (e.g. depression). Service providers identified as needing more training around sexuality. | Limitations: small sample size |

| Hasan T, Muhaddes T, Camellia S, Selim N, Rashid SF. | 2014 | India | 226 women with physical, visual or hearing disabilities from ages 14. 3 were ages 14-19. | To investigate the prevalence of intimate partner violence in a sample of women with disabilities | mixed methods - survey and interviews with sub-sample | 84% reported an experience of abuse. 103 out of 226 reported having experienced forced sex. More common was emotional and physical abuse. Participants reported that violence was due to their disability, not being able to pay dowry, or their lower economic status. Some reported than some men chose to marry women with disabilities in the expectation that they would have to pay higher dowries; these husbands would then become violent during marriage. Less than half (45%) of those who had experienced violence had sought support or help. | Strengths: large sample. Limitations: self-report data |
|--|------|---------|---|--|--|---|---|
| Hatton, S., Tector, A | 2010 | USA | Young people with autism and Asperger's. | To develop an appropriate sexuality and relationship curriculum for students with autism | Mixed methods - questionnaire and interviews | Young people with autism and Asperger's reported receiving sex education at school, and showed adequate levels of knowledge, but wished they had received more education at school about relationships. Some reported sexual relationships as difficult because touching was an unpredictable potential sensory barrier. | Limitations: very small sample, and institution specific. |
| Healy E., McGuire B.E., Evans D.S., Carley S.N. | 2009 | Ireland | 32 (12 female) people with intellectual disabilities ages 13 and over (no females under the age of 18). | To assess the sexual knowledge, sexual experiences and aspirations of people with intellectual disabilities | Qualitative - focus groups | Adults over the age of 18 had an understanding of their sexual rights, but reported various social and cultural barriers to achieving sexual autonomy. Some resorted to secrecy and deception to exercise their sexuality. Those under the age of 18 had only basic knowledge of sexual issues (e.g. pregnancy), but aspired to having relationships and being married. Family and staff attitudes (mainly reported as reluctant) were reported to be very influential. | Limitations: Small sample. No girls under age 18 |
| Heller M.K., Gambino S., Church P., Lindsay S., | 2016 | Canada | 12 young people (ages 16-25) with physical disabilities | To explore how young people with Spina Bifida think about sexuality and discuss | Qualitative - interviews | Most participants expressed anxiety about having to disclose their disability (where not visible) and aspects of their disability (e.g. incontinence) to potential partners, for | Strengths: first such study. Sample includes different sexualities. Limitations: Small sample size |

| Kaufman M., McPherson A.C. | | | (Spina Bifida). 8 females. | sexuality and their disability with their partners | | fear of potential rejection. Anxiety about discussing Spina Bifida-specific sexual health needs (incontinence). Participants reported being excluded from sexual health education at school, but have received some sexual health knowledge from other sources (e.g. internet). They reported receiving minimal Spina Bifida-specific sexual health education. | |
|---|------|------------------------|---|---|--|---|--|
| Hershkowitz I., Lamb M.E., Horowitz D. | 2007 | Israel | 40430 abuse victims aged 3-14 years over a 6 year period (11% children with minor disabilities; 1.2% children with severe disabilities). | To examine the characteristics of abuse reported by children with disabilities as reported in forensic statements | Quantitative | Children with minor disabilities slightly more likely to have been suspected sexual abuse victims than non-disabled (41.1% vs 38.7%). Children were severe disabilities more likely (49.8%). Children with minor and severe disabilities failed to report abuse more often than non-disabled children, and where they did report they were more likely to delay reporting by at least one month. Children with disabilities alleged more serious offences. Children with severe disabilities had lowest level of understanding sexual abuse and suspects' motives. | Strength: large representative sample |
| Hilberink S.R., Kruijver E., Wiegerink D.J.H.G., Vliet Vlieland T.P.M. | 2013 | The Netherla nds | 14 young people with physical disabilities (3 females) ages 14- 31. | To evaluate a group sexual health education programme for young people with physical disabilities. | Quantitative - pre- and post- intervention questionnaires | Education sessions were positively received. Attenders reported a decrease in difficulty discussing sexuality with their partners. There were no changes regarding sexual self-esteem and self -efficacy. Effectiveness was moderate | Limitations: small sample size |
| Howard-Barr E.M., Rienzo B.A., Morgan Pigg Jr. R.M., James D. | 2005 | USA | 206 teachers of young people with intellectual (mental) disabilities. | To explore the beliefs, preparation and practices of teachers teaching sex education to students with disabilities | Quantitative - survey questionnaire | Less than half (44%) reported teaching any sexuality education. However, some relevant topics were taught but did not seem to be understood as part of "sexuality education". Teachers rated personal skills topics as more important than developmental topics (such as | Strengths: good sample size and representation of teachers |

| | | | | | | reproduction). Less controversial topics tended to be taught - e.g. concept of sexual behaviour rated as least necessary to teach. Teachers rated their preparation to teach sexuality as inadequate. | |
|---|------|--------|---|---|------------------------------------|---|--|
| Isler, A., Beytut, D., Tas, F., Conk, Z. | 2009 | Turkey | 42 parents of children (ages 15- 21) with mild to moderate intellectual disabilities | To investigate the knowledge, attitudes, opinions and concerns of parents regarding the sexuality of their child with intellectual disability | Quantitative - questionnaires | 75% reported never having received any professional education on disability sexuality. 32.5% never talked about sexuality with their children. 55% of parents thought that sexuality education should be provided during elementary school. Many had negative attitudes about masturbation. 57.5% of parents talked to their children about puberty, and 27.5% spoke about reproduction. The majority had concerns about their children's future. | Limitations: descriptive data |
| Jahoda A., Pownall J. | 2014 | UK | 30 adolescents (ages 16-21) with mild intellectual disabilities (14 female), and comparison group of 30 non-disabled adolescents | To compare sexual knowledge and sources of information between adolescents with mild intellectual disabilities and non- disabled adolescents | Quantitative - questionnaires | Participants with disabilities had significantly lower levels of sexual knowledge, with females with disabilities having lowest levels of knowledge. Non- disabled females had highest levels of knowledge. There was no significant differences in level of knowledge along IQ scores for disabled participants. Participants with disabilities used significantly fewer sources of information. | Strengths: comparison group. Limitations: small sample size |
| Jaudes P.K., Mackey- Bilaver L. | 2008 | USA | 101189 children aged 6 or below. 49% female. 29.7% white. 4.2% had a developmental/inte llectual disability, 6.1% had psychiatric disability, 24.1% had chronic physical condition. | To examine whether chronic health conditions place children at risk of maltreatment | Quantitative - case report data | 11.7% had reportedly suffered abuse of neglect. Children with psychiatric disabilities nearly 2x as likely to have been abused or neglected. Risk of abuse was only slightly higher for children with chronic health conditions compared to children with no disabilities. Children with intellectual/developmental disability faced no increased risk. | Large sample. Limited information about nature of abuse. |

| Jemtå L., Fugl-Meyer K.S., Öberg K. | 2008 | Sweden | 141 (68 females) children and adolescents (7-18 years) with physical disabilities. | To explore experiences of intimacy and sexuality, and exposure to sexual abuse, among children and adolescents with physical disabilities | Quantitative - questionnaire and interview data | 46% of age 7-12 cohort reported being in a girlfriend/boyfriend relationship. All relationships were opposite sex. Intimate acts included kissing and hugging. 55% of age 13-18 cohort had experienced a heterosexual relationship. A majority had taken part in intimate acts and caressing. Only a minority (15%) reported being in a sexual relationship. 15% of adolescents were concerned about future sexual experiences. Among adolescents, 7% (1 boy and 3 girls) reported sexual abuse. A majority expressed future aspirations of living with a partner and having children | Strengths: included young children |
|--|------|----------|---|---|--|--|---|
| Joshi, G.A., Joshi, P.G. | 2015 | India | 30 girls with different disabilities in residential institution | To describe the menstrual patterns of girls with disabilities | Quantitative | Girls with intellectual disabilities had a later age of menarche, irregular cycles and more behavioural problems. Girls with hearing disabilities and locomotor disabilities had normal menstrual patterns. Girls with visual disabilities had early menarche and regular cycles. Girls with mild intellectual disabilities and girls with no intellectual disabilities were able to take care of personal menstrual hygiene. | Limitations: small sample. Descriptive |
| Kassa T.A., Luck T., Bekele A., Riedel-Heller S.G. | 2016 | Ethiopia | 426 people with disabilities aged 10- 24 years (35.7% females). Disability: Physical (41.5%), visual (23%), hearing (19.2%), intellectual (13.1%), and multiple (3.1%). 19.2% were congenital disabilities | To assess the level of HIV knowledge, attitudes and practice of young people with disabilities in Addis Ababa | Quantitative - cross-sectional survey | 64.6% of respondents had heard of sexual and reproductive health services, but only 26.1% had ever used them. Half (52.1%) perceived services to be inaccessible to people with disabilities. Reasons: inaccessible environment, provider's negative attitudes and disapproval, lack of money, parent's disapproval. The majority had low levels of knowledge about reproduction and reproductive health. Majority (53.3%) had poor knowledge about STDs. Majority (83.8%) had moderate knowledge about HIV transmission, but majority (88%) had poor knowledge about | Strengths: large representative sample. Limitations: no comparison group |

| | | | | | | HIV prevention. Perception of risk for HIV was low (21.6% believed they were at risk). Only 56.1% had gone for HIV testing. 40.6% showed an unfavourable attitude towards reproductive health rights. Majority reported having no sexuality discussion with their parents. Those with intellectual disabilities had lowest levels of sexual and reproductive health knowledge. | |
|---|------|------------------------|--|--|---|--|---|
| Kassa T.A., Luck T., Birru S.K., Riedel- Heller S.G. | 2014 | Ethiopia | 426 people with disabilities aged 10- 24 years (35.7% females). Disability: Physical (41.5%), visual (23%), hearing (19.2%), intellectual (13.1%), and multiple (3.1%). | To explore the sexual and reproductive health status of young people with disabilities sin Addis Ababa | Quantitative - cross-sectional survey | Half (51.9%) had ever had sexual intercourse. Most (75.1%) had first sex between 15-19 years (females earlier than males). Only 34.8% had used contraception. 11.8% reported their first sexual experience as rape. 58.8% had multiple lifetime sexual partners. 23.5% had a history of STD, 27% had used drugs and 54.5% had used alcohol before. 55.6% of females had at least 1 pregnancy in the past (most were unintended). 55% of these had a history of abortion. | Strengths: large representative sample. Limitations: no comparison group |
| Katz G. | 2001 | Canada | 6 adolescents and young adults with developmental disabilities | To describe examples of problems encountered on the Internet and with computers generally | Qualitative | Respondents reported on examples of online emotional and sexual victimization. | Small sample size; ONLY ABSTRACT AVAILABLE |
| Kef S., Bos H. | 2006 | The Netherla nds | 36 (16 female) adolescents and young adults who are blind (mean age 21.2yrs). | To investigate sexual knowledge and behaviour, and psychological adjustment of adolescents who are blind | Quantitative - questionnaires | 92% of respondents felt they had sufficient information about sexuality. Respondents turn to their parents (33.3%), media (30.6%), and friend (19.4%) for information. Almost half (47.2%) reported experiencing overprotection by their parents regarding sexuality and dating. 75% reported having had romantic partners. 13 of 24 who answered a question about sex, reported having had sexual intercourse. just over half of these had had sex before age 18. Overall, participants reported a high level of | Limitations: small sample size. No comparison group |

| | | | | | | self-esteem. Respondents who reported more parental overprotection, had lower scores of self-esteem and were relatively older at age of first sexual experience | |
|-----------------------------|------|----------------|---|--|---|---|---|
| Kijak R.J. | 2011 | Poland | 133 young people with severe intellectual disability aged 17- 25. And a control group of 133 non- disabled. | To investigate the sexuality and sexual education of young people with intellectual disabilities | Quantitative - medical examination records | Young people with intellectual disabilities reached sexual maturation (boys and girls) on average 2 years later than non-disabled. The women with intellectual disabilities did not appear to use the services of a gynaecologist. Males were unable to test their testicles and females unable to test their breast, and such medical examinations were not provided for. Most participants notice the physical changes in their body as a result of puberty, but do not understand these changes. They had extremely low levels of knowledge about contraception and STDs. | Strengths: few studies that looked at severe intellectual disabilities. Use of a comparison group. Limitation: not a conventional research article |
| Kim, Yu-Ri. | 2016 | South Korea | 3 girls (ages 11-13) with mild and moderate intellectual disabilities | To evaluate the effectiveness of a sexual abuse prevention intervention for children with intellectual disabilities | Quantitative - pre-and post- intervention scales. Intervention - use of 9 role play scenarios, story cards and anatomical posters and other materials | Improvements in knowledge and refusal and reporting skills were observed, and maintained at 10-week follow-up | Limitations: very small sample size |
| Klett L.S., Turan Y. | 2012 | USA | 3 girls (ages 9, 11 and 12) with a diagnosis of autism | To evaluate the effectiveness of a parent-led social story intervention to teach menstrual care skills to young girls with autism | Quantitative - pre- and -post intervention observations of behaviour | Participants gained knowledge about reproductive development and were able to independently undertake their own menstrual care. | Limitations: very small sample size |
| Koetting C., Fitzpatrick | 2012 | USA | 43 nurse practitioners (about children with | To assess knowledge level of nurse practitioners of | Quantitative - questionnaires | Nurses had deficits in identifying parts of pre-pubescent female genitalia, and the majority did not check genitalia in regular | Limitations: self-selected sample |

| J.J., Lewin L., Kilanowski J. | | | cognitive disabilities) | symptoms of child sexual abuse on children with cognitive disabilities | | physical exams. They reported feeling they were not competent to perform this task, and were not aware of policy position of their institution. | |
|----------------------------------|------|--------|--|--|---|---|--|
| Kok G., Akyuz A. | 2015 | Turkey | 84 parents of children (ages 10- 14) with intellectual disabilities | To determine the educational needs of parents with regards to the sexuality of their adolescent child with intellectual disabilities, and the effectiveness of an educational intervention | Mixed methods - interviews and questionnaires | Mothers reported that teaching their daughters about menstrual care was most challenging. Most parents were concerned about teaching their child self-care and hygiene. Many parents were concerned about sexual vulnerability of their child and knowing the right way to respond to their child's sexual development. Information scores and self-efficacy score increased significantly after education intervention | Limitations: volunteer participants (biased towards positive attitudes?) |
| Krupa, C., Esmail, S. | 2010 | Canada | 17 individuals (11 females) with visual disabilities aged 18 and older | To explore the views of people with visual disabilities about how best to approach sexual health education | Qualitative - interviews and focus groups | Participants felt that their disability prevented them from receiving equitable sexual health education, with educators tending to ignore their needs. Participants strongly recommended the use of tactile models in sexual health education, and education around non-verbal communication. Personal safety was a critical concern, including risks to safety when dating. Participants felt that segregated sexual health education classes for disabled and non-disabled was stigmatizing, perpetuating notions of asexuality and undesirability of people with disabilities. | Strengths: provides insight to what is helpful in sexual health education. Limitations: small sample size |
| Kvam M.H. | 2000 | Norway | 26 hospital with paediatric departments (about children with disabilities) | To investigate the prevalence and disclosure of sexual abuse of children with disabilities in Norway | Quantitative - questionnaires | Of the 1293 (78% girls) reported examined cases of suspected child sexual abuse, 54 girls and 29 boys had a disability (mostly cognitive and intellectual disability and physical disabilities). 68% of these were between 7-10 years. Children with severe disabilities only constituted 1.7% of those examined children. Disabled children were more often assessed as "probably | Strengths: use of national medical data. |

| Kvam M.H. | 2004 | Norway | 302 deaf individuals (ages 18-65) who became deaf before the age of 9 years. 58.6% were female | To estimate the prevalence of childhood sexual abuse among deaf children in Norway | Quantitative - survey questionnaire | assaulted" than non-disabled children. Thus when a child has a severe disability, sexual abuse may not be recognised. 45.8% of deaf girls had been exposed to unwanted sexual experiences in childhood. Most of the abuses were repeated. The most frequent type for girls was genital touching and forced sex. When compared to data from hearing population, deaf respondents reported abuse more frequently. Age of first contact of sexual abuse varied from age 3 to 15 (mean age 11). 49% of respondents experiencing sexual abuse with contact did not disclose the abuse to anyone. 10.8% disclosed but were not believed. Most perpetrators were known to the victims | Strengths: large sample |
|--------------------------------|------|--------|--|--|---|---|---|
| Kvam M.H., Braathen S.H. | 2008 | Malawi | 23 women ages 18 to 61 with disabilities: physical (10), blindness (4), albinism (3), deafness (4), and intellectual disability (2) | To explore experiences of violence and abuse against girls and women with disabilities | Qualitative - interviews | Most participants were not aware of any children with disabilities having been abused, but reported that they understood this to be an increasing problem. They noted reference to the myth of HIV cleansing as a risk factor. Few had heard of adult women with disabilities who had been sexually abused, but did not personally know any. Most respondents viewed marriage as important. Most perceived themselves to be less attractive because of their disability, and had fewer expectations on the quality of men as husbands. Many women reported being seduced by men to marry them to have sex with them, but once they fell pregnant they would disappear. Many felt cheated and misled. | Limitations: small sample sizes of specific disabilities |
| Kvam M.H., Loeb M. | 2010 | Norway | 376 individuals aged 18 and older who had become | To investigate reported adverse life experiences among | Quantitative - questionnaires | 36% reported having received corporal punishment in childhood, and 29% experienced bullying. 30% (32% of girls and | Strengths: large representative sample. |

| | | | deaf before the age of 9. | adults who were deaf in childhood | | 28% of boys) reported having experienced sexual abuse before the age of 18. Significantly more mental health problems in adulthood were associated with experiencing sexual abuse in childhood, which increased with severity of abuse. | |
|---|------|---------------------------------|--|--|---|--|--|
| Lafferty A., McConkey R., Simpson A. | 2012 | UK (Norther n Ireland) | 26 family carers, 24 professionals, and 24 frontline staff (about adolescents and young adults with intellectual disabilities) | To investigate attitudes of family carers, staff and professionals to the provision of sexual health education for adolescents and young adults with intellectual disabilities | Qualitative - interviews and focus groups | All participants agreed that the people in their care should receive age-appropriate sexual health education. Respondents reported that in reality sexual health education is inadequately provided. Reported barriers were: dilemmas around protection, lack of training, lack of teaching resources and cultural/religious prohibitions (e.g. use of contraception, or acceptance of masturbation). | Strengths: large sample from different carer perspectives. |
| Lamorey S. | 2010 | USA | 111 special education teachers (for adolescents with intellectual disabilities) | Teachers experiences and views with regards to their and their schools responsibilities in addressing the risk reduction needs of adolescents with disabilities | Mixed methods questionnaire survey | Teachers stated that they had taught risk reduction by default because no one else addresses it. They all felt that parents and other community agents should be involved and teachers should actively collaborate with these agents. Barriers to providing risk reduction education were: lack of affordable and accessible teaching materials, lack of time, and parent opposition. Teachers felt that there was a need for district leadership and guidelines around risk reduction education. | Limitations: small sample size |
| Lefèvre- Chaponnière C. | 2010 | Mozambi que | 30 Youth with disabilities aged 15- 29. Disabilities included physical, visual and hearing. There was also a comparison group. | To assess HIV knowledge, attitudes and practices | Quantitative - questionnaire | HIV knowledge was lower for youth with disabilities than for non-disabled group. Youth with hearing disabilities have least access to HIV information. | Limitations: small sample size. Article not available in English |
| Lin JD., Chen SF., | 2011 | Taiwan | 521 women with physical disabilities | To assess the reproductive health care of women with | Quantitative - self-report questionnaires | 11.3% of women had had a hysterectomy; 27.7% had had a tubal ligation; 3.8% have had cervical cancer; 71.5% of women have | Strengths: large sample. Limitations: not much information specific to girls |

| Lin LP., Sung CL. | | | aged 16 to 96 (mean age 50) | physical disabilities in Taiwan | | ever used a pap smear test (all were over age 20) | with disabilities. Self-report data |
|---|------|--------|---|---|--|---|---|
| Lin LP., Lin JD., Chu C.M., Chen LM. | 2011 | Taiwan | 1152 caregivers of people with intellectual disabilities | To explore caregivers' attitudes about the reproductive health of people with intellectual disabilities, and determinants of gynaecological health for women with intellectual disabilities | Quantitative - questionnaire survey | The majority reported being able to give advice about menstruation and menopause to the women they cared for. However, 46% disagreed that the institution should take responsibility for education. 37.8% reported viewing hysterectomy as an effective way to deal with severe menstrual problems. The majority (96%) felt that more sexual health education is needed and 84% agreed that sex education should begin at preschool age. Most felt confident in providing sex education but 51.7% felt it's not the institution's responsibility. | Strengths: large sample size. Limitations: descriptive, self- report data |
| Lin LP., Lin PY., Chu C.M., Lin J D. | 2011 | Taiwan | 1152 caregivers of people with intellectual disabilities | To explore the predictors of support behaviour of caregivers towards the reproductive health care of women with intellectual disabilities | Quantitative - questionnaire survey | 69.4% of respondents were supportive during menstrual cycle of the women they cared for. The. Most provided support around prevention of sexual abuse in the form of education. Most (over 60%) did not teach clients to examine their breast or arrange pap smear tests for their clients | Strengths: large sample size. Limitations: descriptive, self- report data |
| Lindblad, F., Lainpelto, K. | 2011 | Sweden | 14 district court cases of children (13 females) with a developmental disability (autism, intellectual disability, ADHD) who had been allegedly abused. | To investigate arguments of the Swedish criminal courts when a child with neuropsychiatric disability has allegedly been abused | Quantitative - analysis of court records | Psychiatric experts were engaged in only 2 of the 14 cases, where the focus was on credibility issues. When experts were not engaged, the arguments used focus on developmental issues. So developmental issues were not argued with the help of a psychiatric expert | Strengths: actual court records. Limitations: descriptive and small sample |
| Lindsay W.R., Smith A.H.W., Quinn K., Anderson A., Smith A., | 2004 | UK | 18 women with intellectual disabilities aged 17- 59 (these were the only women out of a total 202 offenders with | To explore the characteristics of female offenders with intellectual disabilities | Quantitative - analysis of case records | 9% of the total cohort of offenders were female. 16.5% of female offenders were aged 17-19. 67% also had a diagnosis of mental illness. 5.% of female offenders had committed a sexual offence. For 61% of the female offenders, there was a strong suspicion that they had experienced sexual | Strengths: actual case records. Limitations: sample size of women is small. |

| Allan R., Law | | | intellectual | | | abuse in childhood or adolescence. Far | |
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| J. | | | disabilities. | | | fewer men had been sexually abused. | |
| Linton K.F., Rueda H.A. | 2015 | USA | 13 high school social workers (working with adolescents with various disabilities) | To explore the dating and sexual experience of youth with disabilities who are ethnic minorities | Qualitative - interviews | Adolescents internally influenced by family values and culture, and spoke about males tending to be more valued than females; Hispanic individual discouraging contraceptive use. Adolescents who reported abuse tended to do so with an attitude of acceptance, and many had a history of physical or sexual abuse. Ethnic minority adolescents with disabilities tend to come from more socioeconomically under resourced households; many lived with extended families. Social workers felt that families did not discuss or support their disabled child with issues of sexuality. | Limitations: small sample size |
| Linton KF, Rueda HA. | 2014 | USA | 13 high school social workers (working with adolescents with various disabilities) | To explore the sexuality and pregnancy experiences of adolescents with disabilities, from the perspective of social workers | Qualitative - interviews | Social workers viewed adolescents with emotional disabilities as impulsive and lacking in judgment and unable to discern consequences, and lacking in social and interpersonal skills. Adolescents with intellectual disabilities were further viewed as lacking the capacity to understand sexual issues. Social workers saw the adolescents as sexually vulnerable, and at risk of engaging in sex as a means to combat low self-esteem, particularly girls with disabilities, who are then more vulnerable to coercion and manipulation. Social workers also report that adolescents with disabilities tended to not use contraception, because of lack of access to contraception or feeling unable to communicate on contraceptive use. Social workers felt that their attempts at discussing sexual health and protection were in vain, with adolescents falling pregnant. | Limitations: small sample size |

| Liou WY. | 2014 | Taiwan | 196 female high school students with intellectual disabilities (15.3% also had a physical disability). Ages 14 to 18. | To develop an illustrated sexual abuse prevention scale with female adolescents with intellectual disabilities | Quantitative - questionnaire | Participants had more knowledge regarding puberty, body boundaries and identifying improper sexual contact, and less knowledge about identifying abusive situations, and coping with abusive situations. | Limitations: study focuses more on validating scale, and provides minimal findings related to knowledge |
|-----------------------------|------|--------|---|--|--|--|--|
| Löfgren- Mårtenson L. | 2012 | Sweden | Youth with intellectual disabilities (16-21) enrolled in special education high schools | Explore experiences of sex education and their view on how sex education should be taught to youth with IDs. | Qualitative: In- depth interviews | Sex education focuses primarily on heterosexual identity. There is a need for more positive and strengthening sex education for youth with IDs; encouraging them and assisting them to explore and develop their own sexuality and strategies to avoid abuse and exploitation. | Reluctance of the sample to criticize the education they get. May result in overly- positive responses. However; results are similar to those found in other studies. |
| Löfgren- Mårtenson, L | 2004 | Sweden | Youth with intellectual disabilities brought up in a family environment, and not in institutions. | Explore possibilities and hindrances for sexuality and love for youth with intellectual disabilities. How staff members and parents connected with youth with ID shape their sexuality. What influences sexual expression among youth with IDs. | Qualitative: participant observation at dances for youth with IDs and in-depth interviews with youth with IDs, parents and staff members (from recreational environments, group homes, student homes and short-term homes) | Sexuality is shaped by cultural context, girls in Sweden are empowered, also girls with IDs, which is reflected in their sexual exploration and expressions, youth with IDs express a need for love, romance and sexual expression, youth with IDs lack privacy and independence to explore romance and sexuality, alternative sexual expression is made difficult in controlled environments (where staff and parents are primarily concerned with teaching the youth to be sexually and romantically appropriate. Alternative expressions are often misunderstood to be misdirected expressions that need to be adjusted, rather than expressions of homosexuality), lack of guidance for parents and caregivers on how to deal with sexuality among youth with IDs. | |
| Löfgren- Mårtenson, L | 2009 | Sweden | Youth with intellectual disabilities (16-27) brought up in a family | Explore opportunities and hindrances for young people with intellectual disabilities (ID) in expressing a | Qualitative: participant observation at dances for youth with IDs | Homosexuality is uncommon among youth with IDs. Why? - Youth with IDs are dependent on and imposed upon support and control in their sexual development | |

| | | | environment, and not in institutions. | variety of sexual expressions, and examine in which way the influence of environment may impact the sexuality of young adults with ID | and in-depth interviews with youth with IDs, parents and staff members (from recreational environments, group homes, student homes and short-term homes) | Lack of role models, support and opportunities for exploration and development of alternative sexualities Encourage increased focus on sexual variation in sexual education programmes and strategies targeted at this group. | |
|-----------------------------|------|-----------------|---|--|---|---|---|
| Lund E.M., Hammond M. | 2014 | USA | Adults with intellectual disabilities | Explore the potential usefulness of a one- session psychoeducation curriculum for adults with intellectual and developmental disabilities living in rural areas. | Qualitative, implementation of one day course on abuse (SAFE intervention) and evaluation of the course based on observations of course facilitator and oral comments made from workshop participants and program staff. | SAFE intervention: One-session course targeted at people with IDs, covering: financial, sexual, physical and verbal abuse, neglect, victim-blaming, and reporting abuse. Preliminary positive feedback from course conveners and participants, particularly good with one-session for rural areas. More relevant for individuals with mild and moderate IDs than those with severe IDs. Still need to measure efficacy of intervention. Important to use multiple forms of media, repetitions, flexibility and scenario based teaching to educate people with IDs. Need to target individuals with low functioning specifically. | Need for more methodologically rigorous research to confirm preliminary findings of this study. Need to evaluate efficacy of the programme. |
| Maart S., Jelsma J. | 2010 | South Africa | Cross-sectional sample drawn from learners with physical disabilities in special schools between grades 8 and 9 in Cape Town. 91 | Compare the sexual behaviours of adolescents with physical disabilities to those of their non- disabled peers. | Survey: South African youth risk behaviour survey. A cross- sectional, descriptive and analytical | Disabled adolescents are indulging in risky sexual behaviours, and are at equal or increased risk as compared to their non- disabled peers of developing HIV. ¼ of the disabled youth and 1/3 of general population reported to be sexually active. They are engaging in high-risk sexual behaviour: early onset of sexual activity, | Strength: The sample match the general population of South Africans with disabilities in terms of race, gender and socio-economic status, and thus results can likely be generalised to all South African disabled |

| | | | participants, 56 % male. | | research Design. Compared with National survey on | multiple partners, sex without condom and substance use, and low perceived risk for HIV. Females tend to begin sexual activity earlier than their non-disabled peers. Could be due to low self-esteem and body image. A finding not consistent with the literature was that the likelihood of having been physically forced to have sex was similar between adolescents with disability and their able-bodied peers. | adolescents. Limitations: Limited to youth with physical disabilities, excluding youth with developmental and intellectual disabilities. |
|----------------------|------|-----------------|---|---|---|---|---|
| Maia A.C.B. | 2016 | Brazil | 12 people with intellectual disabilities ages 18 - 39. Four women and eight men. Selected from a special needs educational institution. | Investigate the experience of sexuality and sexual health from the point of view of persons with ID and, more specifically, the understanding that they have about sexuality and the expectations of affective and sexual relationships, and prevention behaviours and sexual education received. | Qualitative - individual interviews | Participants have a restrictive view of sexuality and the sexual body. Participants express sexuality and wish for love and romance, but they experience lack of privacy and overprotection, limiting their opportunities for exploring and expressing sexuality. They are seen and treated as 'eternal children', underestimated, giving parents legitimacy for overprotection and control. Rejects myths of people with IDs being asexual or oversexed with uncontrollable sexual behaviour. Informants experience lack of information about sexuality. Cite TV and internet as main sources of information. The sex education and information they get is largely about preventing unwanted pregnancies, STDs and abuse. Education is highly gendered, with the preventive discourse being particularly strong for girls. | Limited sample of 12 people |
| Mall S, Swartz L. | 2014 | South Africa | 27 educators and carers in special schools for deaf and hard-of- hearing adolescents | Explore attitudes of educators working in schools for Deaf and hard-of-hearing pupils in South Africa toward condom education for their pupils | Qualitative - interviews and focus groups | Educators were aware of HIV risk for Deaf students, but none of the schools had a clear and written strategy for condom education. Some educators were positive to this education and had no limitations, other teachers had limitations, primarily related to moral and religious beliefs and issues. | Only selected schools in two cities in SA, but selected all the relevant schools in Cape Town. |

| | | | | | | Many of the special schools for this group are religiously based, and in these schools reluctance to condom education is generally stronger (especially in Catholic schools). It is up to the teachers individually to decide if they provide the children and youth with condom education. Due to scarcity of special schools for this group, a religious school is often the only option available. | |
|---------|------|-----------------|--|--|-----------------------------|---|-------------------------------------|
| Mall S. | 2011 | South Africa | 9 parents of deaf and hard-of- hearing adolescents | Explores parents of deaf and hard-of hearing adolescents' anxieties about HIV risk | Qualitative - interviews | Parents are aware of the risk for HIV/AIDS for their Deaf/ hard of hearing children, due to premature sexual activity or exposure to sexual abuse. Parents saw the importance of them discussing issues of sexuality, condom use, and healthy relationships choices with their children. Most parents advised the children to be abstinent until end of high school. Parents believed that the special schools their children were attended provided adequate sexual education. Parents had heard about the myth of virgin rape, and fared that this would put their children at risk for abuse. Some parents experience difficulties communicating with their children due to lack of ability to communicate in sign language on the parents' side. Parents need better access to sign language classes to improve communication. Parent-child communication is a key factor in developing a healthy sexuality. Parents also mentions factors other than the disability that put their children at risk for HIV/ AIDS, these factors are poverty, abuse and violence endemic to the areas where many of them live. Parents need assistance in strategies for negotiation and communication with | Small and biased sample of parents. |

| | | | | | | their children with regards to safe development and exploration of sexuality. Some parents are over-protective, which may lead to rebellious behaviour by the youth, or limitations in their sexual development. | |
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| Mall S., Swartz L. | 2012 | South Africa | 28 staff at schools for deaf and hard- of-hearing adolescents | Explore perceptions of educators of deaf and hard of hearing adolescents of the HIV- risk factors to which their learners are exposed | Qualitative - interviews and focus groups | Educators were aware the risks and vulnerability for HIV infection for the learners with hearing impairment. They believed that these young people are particularly vulnerable to infection because of their increased vulnerability for sexual abuse, their engagement in higher risk sexual behaviour and excessive use of alcohol and/ or drugs. There is a need for programs on sex education and substance use/ abuse particularly for youth with hearing impairment. Educators for this group also need training on these issues to best education this group. | Small qualitative study, rely on reports only from educators, challenges with interpretation to English (interpreter did not have English as first language). |
| Mallén A. | 2011 | Sweden | 14 professionals working in child and youth habilitation services reporting abuse of children with disabilities | The aim of this study is to discuss why some cases of abuse and neglect of disabled children are considered difficult to report by the Child and Youth Habilitation Services in Sweden. | Qualitative - interviews | Reporting abuse was seen as a 'last resort' and used only when all other remedies that are seen as less punitive had been exhausted. The main obstacles to reporting were the perceived closeness between staff members and the disabled children's families; they fear destroying the close relationship. Other obstacles were habilitation ideals, cultural ideas about the family, a lack of evidence of abuse and neglect, and uncertainty about the children's future after reporting. Factors that facilitated reporting were visible proof of abuse and neglect, and the disabled children's ability to communicate. Certain criminal acts against the children were seen as more reprehensible than others and thus easier to report. Sexual violence; girls who | Strength: combination of individual and group interviews. Groups: natural groups (people who are familiar with each other): allows for observations of established group dynamics. |

| Mandell D.S., Eleey C.C., Cederbaum J.A., Noll E., Katherine Hutchinson M., Jemmott L.S., Blank M.B. | 2008 | USA | 512344 children ages 12-17 receiving Medicaid, of whom 8015 were children with disabilities (various types) | The aim was to estimate the relative risk of sexually transmitted infections (STIs) among children identified as having learning disabilities through the special education system. | Quantitative - cross-sectional study using special education data and Medicaid data. | experience this are expected to withdraw and keep her feelings to herself, while boys are expected to act out more. If their behaviour is outside the expected gender- norm, makes them less believable. Children/ youth with learning disabilities are at similar or increased risk for contracting STIs as compared to other youth. Girls have higher rates than boys in both groups. There is a need for studies to understand the risk behaviours and risk reduction needs of this group. | Limitations: The definitions used to identify children with learning disabilities in the data, and definition of STIs. It is likely that both are underestimated. |
|---|------|--------|---|---|--|--|--|
| Mansbach- Kleinfeld I., Ifrah A., Apter A., Farbstein I. | 2015 | Israel | 906 adolescents (121 with a learning disability and 54 with hearing disabilities) | The objectives of the study were to assess the prevalence of child sexual abuse (CSA) in a nation-wide representative sample of 14–17 year old Israeli adolescents, and to exam-ine the associations between CSA, socio- demographic correlates and various measures of physical and mental health. | Quantitative - representative sample of Israeli 14-17 year olds | Child sexual abuse was reported by 3.3% of adolescents. Higher risk of exposure to CSA was found among girls, among adolescents living in a one-parent household and among adolescents with a chronic disability. In multivariate models adjusting for gender, learning disabilities and depression, CSA was associated with suicidal attempts, stomach ache, dizziness, sleep problems, well being at home and bullying behaviours. Associations between CSA and suicide should be further examined, as well as associations between CSA, disability and gender. | The main limitation is the cross-sectional nature of the study, which does not allow inferences about the antecedents and consequences of CSA, although it does allow for analysis of important associations between CSA and different correlates. Relatively small sample size limited analysis of associations of CSA and disorders with low prevalence. The young age of the interviewees may result in under-reporting. |
| Martin S.L., Ray N., Sotres- Alvarez D., Kupper L.L., Moracco K.E., Dickens | 2006 | USA | 5326 women ages 18 and above, of whom 26% had a disability | Examine whether women's disability status is associated with increased risk for physical and sexual assault. | Quantitative - survey; NC- BRFSS, an ongoing random-digit dial household telephone | Women with disabilities are not significantly more likely than women without disabilities to experience physical assault, but they are more than four times more likely to experience sexual assault compared to women without disabilities. Intimate partners (current or past) are the | Use of telephone surveys biases the sample towards households with telephones. This may exclude informants with communication challenges, such as people with hearing and |

| P.A., Scandlin D., Gizlice Z. | | | | | survey of a representative sample of noninstitutionali zed adults (age 18 years and older) collecting information concerning an assortment of health and sociodemograp hic variables. 5,326 women serve as the study sample for the current research. | most commonly reported perpetrators. Those particularly at risk were young women, non-white women and unmarried women. There is a need for more interventions, improved screening to identify victims of abuse, accessible services to women with various types of disabilities. | communication problems. People living in institutions were excluded. The sensitive nature of the topic makes it difficult to research. This is likely to lead to underreporting and not over- reporting, making the conclusions relevant. |
|-------------------------------------|------|--------|--|--|---|---|---|
| Mccabe J., Holmes D. | 2014 | Canada | nurses providing sexual health care to adolescents with developmental disabilities and/or physical disabilities | To explore the experiences of nurses providing sexual health care to adolescents with physical and/or developmental disabilities, with attention to the institutional and social discourses that shape these interactions. | Qualitative - ethnography study including interviews, key informant discussions, documentary evidence and observation of institutional setting. | Nurses occupy and strive to maintain, the role of a caring agent. However, aspects of the clinical, institutional and broader social environments may undermine their ability to promote sexual health to youth with disabilities. In nurses' efforts to maintain therapeutic relationships with clients, sexual health is often medicalised to legitimize it as an appropriate topic of discussion with patients and families. Facilities serving youth with disabilities should take steps to address barriers to the delivery of sexual health promotion and several solutions are proposed. Studies into the experiences of youth with disabilities in the healthcare setting are required, particularly to understand the impact of medicalising sexual health and to improve the delivery | Limited data collection to one facility. Limited pool of informants. However, data saturation was accomplished. |

| McCarthy, | 2011 | UK | 162 doctors | The aim of this study | Quantitative - | of sexual health care. Need for similar research in other communities and facilities for a broader picture. Also need to include the perspectives of families/ carers. There is a need for space and time in the clinical practice for sexual health promotion, as well as capacity building of staff on how to handle youth with disabilities. Most of the GPs had very few women with | Lack of validated survey tools |
|--|------|--------|---|---|---|--|---|
| M | | | (general practitioners), the majority having 10 or fewer women with intellectual disabilities on their caseload | was to explore the prescribing practices and attitudes of General Practitioner's (GP) when women with intellectual disabilities come to them for contraception. | cross-sectional survey | intellectual disabilities in childbearing age among their patients, and very limited experience prescribing contraceptives to this patient group. Need for training and support of GPs to best care for this patient group, for instance from health care professionals who have extensive experience providing care for this group. This will improve and enable patient choice and control. GPs report multiple and sometimes competing interests when considering contraception for this group; the individual herself, parents, family, caregivers and interest of a potential child. Carers and parents are often described as overprotective and pushy towards GPs. GPS must also consider the ability of the girl to consent to sex, this includes a consideration of age and consideration of their intellectual ability. GPs were not clear on how they dealt with girls with low intellectual ability. Women with intellectual disabilities should be told of advantages and disadvantages of contraception, in order to make an informed choice. This appears not be done appropriately. | and limited amount of questions and ability to follow-up to gain more depth. Responses may be skewed toward those who have a particular interest in and awareness of this patient group. |
| McClelland A., Flicker S., Nepveux D., | 2012 | Canada | 10 LGBT people ages 17-26 with | This study aimed to explore the ways in which social and | Qualitative - interviews and focus groups | Participants reported limitations to their autonomy by authority figures. This resulted in behaviour that led to unsafe | Small sample, only individuals with intellectual disabilities, and thus not transferable to |

| Nixon S., Vo T., Wilson C., Marshall Z., Travers R., Proudfoot D. | | | intellectual disabilities | environmental conditions influence vulnerability to adverse sexual health outcomes for this population. | | sexual practices. In the context of virtual prohibition of their sexual activity within their homes, LGBT youth labelled with intellectual disabilities resort to uncomfortable and risky physical and social spaces for romantic and sexual encounters. Consequences of this include less physical safety, reduced opportunity for healthy decision making, less privacy, and unprotected sex. Contrary to stereotypical assumptions, youth with intellectual disabilities are discovering and exploring their sexuality, but they experience more external controls over their autonomy than others their age. Future work should continue to explore how the intersecting identities of being young, LGBT and labelled with an intellectual disability may compound vulnerability to HIV and STI. There is a need for more environments, programs and strategies for sexual health promotion for youth with IDs who identify as LGBT, both targeting educators and youth with IDs. Strategies should be developed in collaboration with the target group. | other disabilities. Results are slightly skewed towards males. |
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| McConkey R., Ryan D. | 2001 | UK; Ireland | 150 staff working with people with intellectual disabilities | Study experience of staff across a range of service settings and providers of dealing with incidents of a sexual nature. | Quantitative - cross-sectional survey | Two-thirds of the staff had experienced being faced with situations (questions/ specific situations) regarding the sexuality of their clients. Only one in five had received training in dealing with these issues. More training had been provided towards understanding the vulnerability of this particular group, which may result in over-emphasis in avoiding abuse (also sexual) and thus put unnecessary restrictions on the sexual development of the youth. Staff in residential facilities felt | Limitation: Self-selected respondents from only one geographical area. |

| McCormack B., Kavanagh D., Caffrey S., Power A. | 2005 | Ireland | 250 cases of alleged sexual abuse in a community-based service (incl young people with intellectual disabilities) | Longitudinal large- scale study of sexual abuse in intellectual disability services, patterns in disclosure, investigation and outcomes, and incidence and trends. | Quantitative - analysis of case report data | better equipped to deal with issues around sexuality than staff in day facilities. There is a need for staff training and policies that spans agencies and results in common approaches to client sexuality. More research is needed on the ability of staff to handle issues of sexuality, also from the perspective of the clients. More than half of the abuse reports were made by the victims themselves, followed by family members of the victims and staff. Almost half of the abuse allegations were confirmed to be abuse through investigation. One in seven cases were classified as possible abuse cases, and a further one in seven were classifies as false or doubtful cases. In almost half the abuse episodes the perpetrator was a peer, also a person with ID. There is a scarcity of guidelines for management and prevention of such type of abuse between peers. There was an increase in abuse reports of the 15 year study period. There is some legislation | Limitations: retrospective data from agency files, reporting was not always consistent. Natural cultural, political and social changes over time may have contributed to increased reporting rates, and thus higher incidence of abuse over time. It is likely that not all abuse has been reported and that figures are understatements. |
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| | | | | | | and guidelines on how to deal with abuse cases when the victim is a child, but not when the victim is a vulnerable adult (such as an adult with ID). Finding a balance between protection from exploitation and abuse, and the right to experience one's sexuality in a positive environment is crucial for such for such legislation. There is a need for increased awareness, improved screening for abuse, for prevention and for | |
| McGee, M.G | 2014 | USA | 6718 adolescents (3520 female), of | Examine the extent to which disability status, | Quantitative - cross-sectional | strategies to deal with abuse cases in both children and in vulnerable adults. Findings revealed that youth with disabilities were significantly more likely to | Limitation: Exclusion of youth not in school, and youth who |
| | | | | alone and in | survey | report exposure to peer victimization, | were not able to complete the |

| | | | whom 1620 had a disability (all types) | combination with other social identities, is associated with differential levels of exposure to peer victimization. | | compared to youth without disabilities. The highest odds of exposure to peer victimization were found among disabled sexual minority males and females. Rates of exposure were higher among females than males. In order to effectively address the problem of peer victimization, it will be important to focus on youth with multiple marginalized identities including disability. Important to consider intersectionality of various identities in future research and strategies to study, prevent and treat abuse. | survey without assistance (may have excluded several youth with disabilities) |
|--------------------------------|------|-----------------|--|---|---|---|---|
| McKenzie J.A., Swartz L. | 2011 | South Africa | 63 participants: 15 community members + 22 parents of children with disabilities + 15 people with disabilities + 12 teachers who work with children with disabilities | Examine accounts of sexuality in children with disabilities in two communities in Eastern Cape, South Africa; the viewpoints on disability in childhood and its implications for sexuality of people with disabilities. | Qualitative - Q- methodology study | Children with disabilities experience stigma and abuse in their communities. Mothers over-protect their disabled children from this stigma and abuse, which contributes to undermining their sexual development, restricting their exposure to the community. Stigma and negative attitudes towards disability also contributes to limit development of a healthy sexuality in disabled children. Sexuality of people with disabilities is seen as different/ outside the normal, which impacts on the self-esteem of disabled children. Sex education in these communities is the responsibility of mothers and grandmothers, who are main caregivers. Sex education programmes should target these care givers, as well as specifically target and focus on children with disabilities, who are often excluded. | |
| McKenzie JA. | 2013 | South Africa | 17 people with disabilities and parents of children with disabilities | Explore experiences of sexuality of disabled people and parents of disabled children in settings of poverty in the Eastern Cape | Qualitative - interviews and focus groups | While sexuality is a very difficult aspect of life for a disabled person due to myths and discrimination against disabled people, it is also an important arena for affirmation and establishing self-worth. It is therefore critical to consider the development of a | |

| | | | | Province of South Africa | | healthy sexuality amongst disabled people and the promotion of their sexual rights. The disabled people interviewed felt that they were less prepared and engaged with their own sexual development compared to their siblings, and they feel that non- disabled siblings are favoured over them. Families were discouraging towards sexual development of the disabled individual; discouraging them from having romantic and sexual relationships, having a family and children. The results is that they do not receive sexual education within the context of the family. In the community disability is shared with stigma and myths; A disabled man proves his worth by having relationships with non-disabled women, while the disabled women is seen to be grateful for sexual contact with a non- disabled person and there is a large degree of suspicion and disbelief surrounding the value of a relationship between a disabled and a non-disabled person. There was disbelief in the ability of disabled people to conceive and bear children as well as their ability to care for their own offspring. | |
|---------|------|-----------------|---|---|---|--|---------------|
| Meel B. | 2009 | South Africa | 1268 attendees at a sexual assault centre, of whom 32 had profound intellectual disability | Study the prevalence of HIV among victims of sexual assault who were children with mental impairment. | Quantitative - analysis of case report data | Over 2% of the sexual assault victims attending the Sinawe Centre were mentally impaired, and the majority of those were female. Of these, 12.5% were HIV seropositive There is need for a larger study related to sexual assault among the mentally impaired, and to take sexual assault cases more seriously so that HIV/AIDS can be prevented in the community. Vulnerable members of society must be protected, and perpetrators must be punished. | Small sample. |

| Miller H.L., Pavlik K.M., Kim M.A., Rogers K.C. | 2017 | USA | 37 children (17 girls) with developmental disabilities aged 7- 19 and their parents | Explore knowledge of sexuality, sexual development and personal safety among a sample of children and adolescents with developmental disabilities referred for an abuse risk reduction programme, as well as from the perspective of their parents. | Mixed methods - interviews and questionnaires | The results suggest that some children with developmental disabilities lack skills to keep themselves safe from abuse. This is confirmed by their own lack of basic understanding of their own bodies, its development and bodily boundaries in terms of what is private. This is also confirmed by parents' concern. Lack of knowledge and understanding may put children with developmental disabilities at risk for abuse, as they may explore their bodies and sexualities in unsafe ways and with people who are not trustworthy. They have difficulties distinguishing appropriate sexual behaviour from inappropriate sexual behaviour. There is need for sex education targeted at this group as well as for their families. | |
|--|------|------|--|--|---|---|--|
| Mirzaee H.S., Mosallaneja d A., Rabbani A, Setoodeh A, Abbasi F, Sayarifard F., Memari A.H. | 2016 | Iran | 642 girls ages 6- 18years with intellectual, physical or sensory disabilities | Assess the sexual maturation of girls with intellectual, sensory and physical disabilities in special schools in Teheran. | Quantitative - cross-sectional survey | The results indicate a slight delay in puberty in this group compared to the general population (which they refer to as 'healthy girls'). This could be attributed to eating disorders, or to side effects of some medications. | |
| Mitra M., Mouradian V.E., McKenna M. | 2013 | USA | 2948 high school students ages 14- 18. 359 girls with disabilities | The aim of this study is to assess the prevalence of dating violence victimization against high schools students with and without disabilities and to examine associations of dating violence with health | Quantitative - cross-sectional survey | High school students with disabilities are at a greater risk for dating violence victimization compared to those without disabilities, girls in both groups are at heightened risk compared to boys. High school girls with disabilities who experience dating violence are at increased risk for experiencing poor mental health outcomes and substance abuse. Further research is needed to explore the context and course | Limitation: People in need of assistance to fill in the questionnaire are excluded from this study. This may have excluded several youth with disabilities. Due to sample size restrictions, could not analyse on group level for physical and emotional disabilities specifically. |

| | | | | risks by disability status among high school girls. | | of dating violence, and its impact on persons with disabilities. There is need for targeted programs for youth with disabilities, and for current programmes and research to include youth with disabilities. | Underreporting in this study is likely. |
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| Montijo, S.S.R., Benítez, Y.G., Bautista, Y.Y.P., García, Á.H. | 2013 | Mexico | 132 young people ages 15-26 with hearing disabilities | Describe demographic profile, history of disability, pattern of sexual behaviour and level of communication with parents about sexual health for young people with hearing disabilities. | Quantitative - cross-sectional survey | Almost half of the respondents had had sex, with an average age of sexual debut of 16,9 years. 72% did not use any contraceptives, 57% reported that their first intercourse was forced and 69,7 had experienced a forced relationship. More than half of the respondents had never talked to their parents about sexual health issues. | |
| Morad M., Kandel I., Merrick J. | 2009 | Israel | females with intellectual disabilities in residential care | Examine the trends of contraceptive methods for females with intellectual disability in residential care centres in Israel. | Quantitative - analysis of case report data | DMPA, an injection contraceptive, is used more often than oral contraceptives in Israel due to the convenience of administration only four times a year and also because it is a highly effective contraceptive. The decision is made by a multidisciplinary team of professionals, the parents/ guardians of the girl and the girl herself (if possible). The right of persons with intellectual disability to their own sexuality has become an emotionally loaded topic among parents, the public, and professionals because of concerns about unwanted pregnancies, venereal diseases, and sexual abuse. | Data collected from annual surveys only give a rudimentary picture of the actual situation in the field. |
| Morales, G.E., Lopez, E.O., Mullet, E. | 2011 | Mexico | 270 parents/family caregivers (75 of whom were caring for a child with Down Syndrome or Neuromotor disorder | Compare the attitudes towards sexual relationships among persons with learning disabilities (PLD) of parents of children without disabilities with the attitudes of | Quantitative - questionnaire | The present study indicates that although there are groups of people that express a low level of acceptability towards the sexual rights of PLD, the majority of the professionals with closer proximity to these persons (68%), as well as a notable part of the lay people (60%), expressed openness toward the sexual expression of the PLD. | |

| | | | | family caregivers (parents of PLD) and with the attitude of professional caregivers (working with PLD). | | The study shows that parents and professionals cannot be seen as a homogenous group, and that their attitudes are largely determined by the nature of the disability of the specific child. Future research should be concerned with creating and testing educative programs that can sensitize the public to the needs and human rights of PLD. | |
|--|------|-----------------|---|--|---|--|---|
| Mprah W.K., Anafi P., Sekyere F.O. | 2014 | Ghana | Seven Ghanian sexual and reproductive health policies and research reports. | Determine if and how SRH policies and research addressed SRH concerns of persons with disabilities. | Qualitative - analysis of policy documents and research reports | Policy documents and research lack attention to people with disabilities. Some documents makes no mention of this group, others do, but only very cursory. There is need for more attention on disability issues in SRH research and policies to make the needs of persons with disabilities visible and to guide and provide disability-friendly services and information. | |
| Mueller- Johnson K., Eisner M.P., Obsuth I. | 2014 | Switzerla nd | 6749 students, of whom 360 had a physical disability | To examine separately for boys and girls whether physical disability is associated with a greater risk of sexual contact and non-contact victimization among a large sample of adolescents in Switzerland, whether physically disabled adolescents are exposed to different risk factors than able- bodied adolescents, and whether physical disability remains a significant risk factor for SV. | Quantitative - cross-sectional survey | While girls with a physical disability have a higher risk than boys with a physical disability to experience SV, the findings suggest that the increase in risk of SV among physically disabled youth is larger for boys than for girls. In fact, once other risk factors, such as for instance child maltreatment and harsh parenting, are taken into account, physical disability is not a significant predictor for SV of girls, but it remains a significant risk factor for boys. This study suggests that strategies for the successful reduction of SV of physically disabled adolescents should primarily target domains such as child maltreatment, the quality of child–parent bonds, and dysfunctional relationships between the parents. | Limited sample, and thus data cannot be generalised to a broader sample of young people with physical disabilities. |

| Munymana JB, M'kumbuzi VR, Mapira HT, Nzabanterur a I, Uwamariyai I, Shema E. | 2014 | Rwanda | 157 people (62.4% female) with physical disabilities aged 5 to 49 | To investigate the prevalence of HIV among people with physical disabilities in Rwanda | Quantitative - blood sample HIV results | The HIV prevalence among the sample of people with disabilities was 5.73% (higher than the population prevalence of 3%). All who tested positive were females. Targeted HIV prevention is required for PWDs in Rwanda, with at least as much rigor as programs targeted towards the general population. Further, this should address the wide range of gender inequalities that make women particularly vulnerable to HIV. Further research needs to be conducted on a larger sample that draws participants from non- institutional settings and from other disability categories; as well as to study the risk factors for HIV infection among PWDs in Rwanda. | Objective measure - ONLY ABSTRACT AVAILABLE |
|---|------|--------|---|---|---|---|--|
| Murphy C., Lincoln S., Meredith S., Cross E.M., Rintell D. | 2016 | USA | 38 genetic counsellors providing counselling to people with intellectual disabilities ages 9- 17 years | Explore experiences of genetic counsellors with being asked to provide sex education counselling, their barriers to and their comfort in doing so for patients with ID ages 9–17. | Quantitative - survey | Caregivers and patients most frequently requested information on puberty, sex abuse prevention, and reproductive health. Genetic counsellors were most comfortable when they could provide sex education counselling within the context of a particular condition or constellation of features. They were least comfortable when they lacked familiarity with the patient, caregiver, or the family's culture. The most frequently cited barriers that prevented genetic counsellors from providing sex education counselling were lack of time, lack of training, the patient's ID being too profound, and a belief that genetic counsellors should not be responsible for providing sex education counselling. Respondents indicated that resource guides specifically designed for use by genetic counsellors would be beneficial to their practice. | Small sample size and low response rate. |

| Murthy G.V.S., John N., Sagar J., Shamanna B.R., Noe C., Soji F., Mani S., Pant H.B., Allagh K., Kamalakann an S. | 2014 | India | 247 women with disability (all types) ages 15-45 (and matched controls without disability) | Compare reproductive health parameters including pregnancy experience, health access during pregnancy and type of delivery among women with disability compared to women with no disability. | Quantitative - case control survey | The study demonstrates that women with disability have a significantly lower pregnancy rate compared to women without a disability. Women with disability have significantly higher risk of co- morbidities like diabetes and depression. Contrary to what has been reported from many countries, parameters related to ante-natal and natal care were similar for women with and without a disability. | Small sample size, especially the sample of women who had experienced pregnancy. |
|--|------|-----------------|---|---|---|--|---|
| Nappi CM, Thakral C, Kapungu C, Donenberg GR, DiClemente R, Brown L; Project STYLE Study Group | 2009 | USA | 718 caregivers and their 13-18 year old adolescents children with psychiatric disabilities | Examine parental monitoring as a moderator of the relationship between quality of family communication about topics related to sexual activity and sexual risk behaviour among adolescents in psychiatric care. | Quantitative - questionnaires | Frequent parental monitoring, under which more open and comfortable family communication about sexual topics is related to decreased adolescent sexual risk taking for troubled African American youth. That is, for African American youth in psychiatric care, greater parental involvement and supervision may be a necessary condition for the protective effect of high quality family sexual communication on adolescent sexual risk taking. Adolescents of parents that perceive themselves as consistent monitors and capable of open and comfortable discourse about sex may be more likely to implement safe sex practices. | Cross sectional design prohibited investigation of causal models. Limited to self- report assessments. |
| Nareadi P.T. | 2013 | South Africa | 32 school staff for adolescents with intellectual disabilities | Explore influences of under reporting of sexual abuse of teenagers with intellectual disability by carers, teachers and social workers. | Qualitative - interviews and focus groups | Findings revealed tendencies for under- reporting due to factors such as: (a) teenagers' limited understanding and communication; (b) family's fear of stigma attached to disability; and (c) professionals' lack of expertise. Extensive training for professionals, families and the entire communities are necessary to sensitise them about their legal obligation to protect and create safe living and learning environments for all children, including those with intellectual disability. | |

| Northway R., Melsome M., Flood S., Bennett D., Howarth J., Thomas B. | 2013 | UK | 47 people with intellectual disabilities aged 18 and over | Explore the views of people with intellectual disability regarding abuse | Qualitative - individual interviews and focus groups | The results show that people with intellectual disabilities can discuss their feelings around abuse and recognise the impact this has on their lives. Sexual abuse was identified by many as the worst form of abuse. Strong views were expressed regarding abuse but what was striking was the continuing negative psychological impact abuse can have on individuals. People with intellectual disabilities are aware that legal and policy provisions should provide justice for victims but also recognise that justice is not always achieved. However, they also identify other strategies that may be useful such as helping abusers to understand the impact of their behaviour on their victims. | No clear definition of abuse was used, which may lead to people speaking about things that fall outside the formal definition of abuse. Informants have mild to moderate intellectual disability. People with severe intellectual disability were not included due to communication difficulties. |
|---|------|-----------|--|--|---|---|---|
| O'Dea S.M., Shuttlewort h R.P., Wedgwood N. | 2012 | Australia | 278 people with physical disabilities (NMD - neuro muscular disorder) ages 18 and over | The purpose of this study was (a) to determine if the levels of sexual expression and interactions with healthcare providers varied significantly between people with and without a NMD, and (b) to explore the extent to which sexual expression and interactions with healthcare providers significantly influenced the impact of NMDs on QoL. | Quantitative - cross-sectional survey | People living with a NMD desire satisfying sexual expression. The current study indicate that the healthcare provider/patient consultation has a moderating effect upon the sexual expression and QoL of people living with a NMD. The interactions with healthcare providers appeared not to act as mediators, but as moderators. The QoL of people living with a NMD deteriorated with respect to an increased level of inhibition of sexual expression, associated with the negative attitudes of healthcare providers. Conversely, when healthcare providers assisted their patients to overcome concerns about sexual expression, the model predicted an increase in QoL. Furthermore, the frequency of sexual activity and fulfilling sexual activity were correlated with a higher QoL. | |

| Oladunni T.M. | 2012 | Nigeria | 140 adolescents with physical disabilities | Determine access of adolescent with disability to sexuality information. | Quantitative - cross-sectional survey | The study revealed poor access to sexuality information for youth with disabilities, resulting in low capacity to manage sexual difficulties and engagement in unsafe sex. The predominant source of sexuality information are peers, while parents and teachers lack the knowledge and skills to provide required information and guidance on sexual matters. Existing national curriculum on family life and HIV/AIDS education does not recognize the sexual and reproductive needs and rights of adolescents with disabilities, leaving a significant population of young people to sexual exploration with negative implications on individual, family and the society. | |
|---|------|---------|--|--|---|---|--|
| Oladunni, T.M. | 2012 | Nigeria | 140 adolescents with physical disabilities | To investigate the sexual behaviour and practices of adolescents with disabilities in Osun State. | Quantitative - cross-sectional survey | More than half of the sample reported to be sexually active, and about 30% reported to have had multiple sexual partners. This is similar to findings in the overall population. This study revealed certain unhealthy sexual behaviours and practices among adolescents with disabilities that have grave consequences on their lives at adulthood. This can be attributed to their poor knowledge of sexual health due to lack of access to sexual information and education. The respondents reported encounters of sexual assault. The outcome of this study indicated that adolescents with disability are highly vulnerable and at greater risk of contracting HIV/AIDS and also a potential risk for new infections. | |
| Olaleye, A.O., Anoemuah, O.A., Ladipo, | 2007 | Nigeria | 103 people with disabilities (all types) aged 10-25. | Explore sexual behaviours and reproductive health knowledge among in- | Quantitative - questionnaire | Severe lack of knowledge and awareness of reproductive health services. Shows that this sample of youth with disabilities are as sexually active as their non-disabled peers, | |

| O.A., Delano, G.E., Idowu, G.F. | | | | school young people with disabilities (PWD) in Ibadan, Nigeria. | | but have lower levels of access to SRH services. 35% were sexually active, 28% had experienced rape, 17% had had or been involved in the procurement of abortion, 43 % had been exposed unwanted intimate behaviour (not penetration/ rape), 40% knew of contraception, 6 % were consistent condom users, half of the respondents had heard about HIV/AIDS. There is an urgent need to develop specific programs for young people with disabilities, especially for those in schools, to address knowledge and behaviour issues regarding reproductive health and HIV/AIDS. | |
|--|------|---------|---|--|----------------------------------|---|--|
| Oosterhoorn , R., Kendrick, A. | 2001 | UK | 20 school staff of children with profound learning and/or physical disabilities | Explores the views of professionals working with children using alternative/augmented communication systems on the issues relating to communication about abuse. | Qualitative - interviews | Awareness of the abuse of disabled children is high among staff and measures are being taken both to try and help the children protect themselves and stress the responsibility of staff to protect disabled children. Due to the severe communication challenges of the children, staff felt that children were not likely to report abuse themselves. The staff felt they were the most appropriate to detect and protect abuse in these children due to their close and daily contact with them. The staff highlighted a need for appropriate training and increased coordination between social work, health and education. | |
| Otte WM, van der Maas F, de Boer A. | 2008 | Nigeria | 119 adolescents (57 blind and 62 sighted) | The aim of this study was to compare the HIV/AIDS knowledge and accessibility to HIV/AIDS information between blind and sighted individuals in Nigeria. | Quantitative - questionnaires | Blindness was found to be associated with diminished knowledge of HIV/AIDS transmission, prevention and symptoms. At the same time, the blind rely on different sources of HIV/AIDS information than sighted respondents. A lack of knowledge and limited accessibility to proper sources of information causes the blind disabled to be more vulnerable. It is necessary to | Due to cultural variations across regions in Nigeria, results are not necessarily representative for other parts of the country, or other countries. Small sample size, and limited to school populations, leaves out out- of-school children. |

| | | | | | | supply them with proper information and increase their HIV/AIDS knowledge targeted specifically at this group. |
|----------------------------|------|-----------------|---|--|---|--|
| Phasha N. | 2009 | South Africa | 12 teachers and 4 police officers (about adolescents with intellectual disabilities) | Views of professionals from police services and special schools for learners with IDs regarding responses to situations of sexual abuse involving individuals with intellectual disability. | Qualitative - interviews and focus groups | Participants shared a sentiment that sexual abuse amongst people with intellectual disability is widespread, and the home, which is supposed to be a safe haven, has in fact become a hub for horrendous forms of potential abuse. The most vulnerable group are those who are out of school. According to organisational protocol at the schools, abuse should be handled in collaboration with the families, as it is a family affair. Sometimes the school and the family disagree on how to handle abuse, and the school often leaves it to the family. This is not also in the best interest of the victim of the abuse, especially if the perpetrator is someone in the family. There is mistrust for the policy and justice system in many families and communities, which prevents them from reporting abuse. Soma African communities prefer to deal with abuse the traditional way, outside the legal system. There is a need for a community approach in prevention and handling of cases of sexual abuse. |
| Phasha T.N., Myaka L.D. | 2014 | South Africa | 17 school and professional staff for adolescents with intellectual disabilities, parents and traditional healers. | Explore factors contributing to the vulnerability of teenagers with intellectual disability to sexual abuse from the perspective of staff working with adolescents with intellectual disabilities | Qualitative - interviews | Informants perceive of adolescents with intellectual disabilities as being particularly vulnerable to sexual abuse. Informants highlight a number of vulnerability factors at individual, family and community level, which highlights that any measures to prevent abuse should occur at various levels. Informants believed that adolescents with IDs were sexually active, and even have a particularly high sex drive. This was linked to their inhibited nature and |

| Phasha T.N., Nyokangi D. | 2012 | South Africa | 16 young people aged 16 to 24 with mild intellectual disabilities | as well as parents and healers. School-based sexual violence experiences of female learners with mild intellectual disability. | Qualitative: In- depth individual interviews and analysis of school documents | tendencies to display sexual feelings, desire and actions more openly. A common conception in the community was said to be that the spirits in people with intellectual disability were so powerful as to make another person wealthy, successful, respected and feared in the community. The belief is that for other people to benefit from this, they have to have sexual intercourse with the person with ID. This puts them at risk for sexual abuse. There is also a belief that people with IDs cannot feel pain or pleasure, and would therefore not suffer from sexual abuse. It was also said that some people have sexual intercourse with a person with ID out of pity, believing that they are undesirable and unattractive. The results indicate that female learners with Ids are exposed to sexual violence. Perpetrators were said to be primarily male peers. The claims that people with intellectual disability have no feelings, do not understand what is happening to them, are promiscuous, and have high sex drives are not substantiated by this study. The study recommends that school policies for sexual violence be intensified and learners receive developmentally appropriate sex education. | Small sample. |
|-----------------------------------|------|-----------------|--|--|--|--|--|
| Philander, J.H., Swartz, L. | 2006 | South Africa | 15 key informants (working with people with visual disabilities) | Views of key informants towards the design, implementation, and evaluation of an HIV prevention program for adolescents with | Qualitative | Informants believed that inadequate education, the lack of accessible information, and the ignorance of sighted people of the sexuality of people with visual impairments foster conditions that are conducive to risky behaviour. Areas that need attention: illiteracy, the inability to | Limited number of informants, and only key informants (not presenting a multitude of perspectives). |

| | | | | visual impairments in South Africa: on areas that need to be included in the design of an HIV/AIDS prevention program for people who are visually impaired. | | read braille, impoverishment, and different levels of development. The participants stressed the needs of women and girls for enhanced self-esteem and relationship skills. They also believed that people with visual impairments are not sufficiently aware of the dangers of HIV and their risk for contracting the virus. Difficulties are both technical; lack of accessible information, and social; social exclusion of people with visual impairment. There is a need for targeted HIV prevention programs for individuals with visual impairments. | |
|-------------------------------|------|-----------------|--|--|---|---|--|
| Pinquart M., Pfeiffer J.P. | 2012 | Germany | 180 adolescents with visual disabilities (and 533 non-disabled peers) | Examine the development of intimate relationships in adolescents with visual impairment compared to their sighted peers. | Quantitative - cross-sectional survey | Adolescents with visual impairment start later than their sighted peers with falling in love, dating, and forming a romantic relationship. However, they catch up, at least as long as they attend special schools for students with visual impairment. Adolescents with visual impairment are not less selective than their peers with regard to criteria for mate selection. To the contrary, they rate emotional maturity of a potential partner as more important than their sighted peers. Third, there is no evidence of lower quality of the romantic relationships of adolescents with visual impairment. | Only respondents from the highest school tracks and only self-report data. May have excluded the most severely disabled or people with multiple disabilities. |
| Potgieter, C., Khan, G. | 2005 | South Africa | 7 adolescents (3 female) with spinal cord injury ages 15- 20 | The aim of the article is to explore the impact of spinal cord injury on adolescent's sexual self-esteem and body image. | Qualitative: in- depth interviews | Despite social constructions of people with disabilities as asexual, unattractive and inappropriate partners, informants in this study are sexually aware human beings. They are interested in sex and are sexually expressive, and most of the participants consider themselves attractive enough for romantic relationships. The study concluded that entrenched socially constructed attitudes appear to limit the | |
| Povilaitiene N., Radzevičien e L. | 2013 | Lithuania | parents and teachers of adolescents with intellectual disabilities | To explore parents and teachers views on the relevance of sex education for adolescents with mild intellectual disabilities | Qualitative | opportunities for spinal cord injured adolescents to express their sexuality more than the limitations by their disabilities. Parents and teachers had differing attitudes. Parents were more passive about teh need for sex education, passing on the function to teachers. Teachers saw sex education as a need and lack of education as a problem, as young people and are sexually active, are sexually unaware. | Small sample. ONLY ABSTRACT AVAILABLE |
|---|------|-----------|--|--|----------------------------------|---|--|
| Pownall J.D., Jahoda A., Hastings R.P. | 2012 | UK | 30 mothers of young people with mild intellectual disabilities (and 30 mothers of non- disabled children) | Compare attitudes and behaviours of mothers of young people with and without intellectual disability with regards to the adolescents' sexual development. | Mixed methods - questionnaire | Both groups placed similar importance on dealing with their children's developing sexuality and were similarly confident in doing so. Mothers of young people with intellectual disability held more cautious attitudes about contraception, readiness to learn about sex, and decisions about intimate relationships. Mothers expressed concerns about their children with intellectual disability and sexual vulnerability. They had also spoken about fewer sexual topics with their children and began these discussions when their children were older. | |
| Pownall, J.D., Jahoda, A., Hastings, R., Kerr, L. | 2011 | UK | 8 mothers of young people with intellectual disabilities | To explore parents experience of supporting their child with disability on matters of sexuality in comparison to supporting their non- disabled child | Qualitative | Mothers reported that supporting their non-disabled child's sexuality was characterised by increasing autonomy, whereas the perceived dependence of their disabled child made such support difficult, as parents were fearful of their child's vulnerability and their child's ability to cope with issues of adulthood. | Small sample size - ONLY ABSTRACT AVAILABLE |
| Radomski D., Jarząbek- Bielecka G., Sowińska- Przepiera E., Milewczyk P. | 2010 | Poland | 30 people with physical disabilities aged 17-41 | To identify specific problems which may occur in gynecological practice related to physical disabilities. | Quantitative - survey | Patients with disabilities report that gynecological care does not meet their needs and expectations and plays no prophylactic role. | Self-report data. ONLY ABSTRACT AVAILABLE |

| Reiter S., Bryen D.N., Shachar I. | 2007 | Israel | 100 adolescents (50 with intellectual and other disability) | The aim of this study was to conduct an exploratory investigation regarding the frequency and type of abuse of a selected group of students with intellectual disabilities in one high school in Israel and compare the findings with the frequency and type of abuse reported by non-disabled youth from similar socioeconomic backgrounds. | Quantitative - questionnaire | The main findings indicate that students with intellectual and other disabilities suffered from abuse more frequently than their peers, and girls more frequently than boys. This difference was more prominent of case of sexual abuse than in cases of physical abuse. Most of the instances of abuse occurred within the close social environment (family, friends, carers, neighbours, etc.) of the victim and were repeated over time. Need for more preventive measures targeted at this group. | Limited to disabled students from one special school. Control group recruitment: geographical spread, but used 'friend-brings-friend' recruitment. |
|---|------|-----------------|---|--|---|--|---|
| Rodríguez, M.Á., Díaz, A.A., Martínez, B.A. | 2006 | Spain | Young people with intellectual disabilities | To describe and evaluate a sexual education programme for young people with intellectual disabilities | Quantitative - pre- and post- intervention questionnaire | There was a significant increase in sexual knowledge after the education programme, which was maintained three months after the program. | ONLY ABSTRACT AVAILABLE |
| Rogers P., Titterington L., Davies M. | 2009 | UK | 335 non-disabled people (about views on sexual abuse of child with physical or intellectual disability) | This study examines the effects victim disability (physical vs. intellectual vs. none), victim resistance (physical vs. verbal vs. none) and respondent gender (male vs. female) have on attributions of blame and credibility in a hypothetical case of child sexual abuse. | Quantitative - vignette-based questionnaire | Males deemed the victim more culpable for her own abuse than did females. Further, perpetrators were deemed more culpable when the victim physically (vs. verbally) resisted. Finally, a significant three-way interaction suggests victim resistance influences attributions of perpetrator blame given a victim's disability status, at least amongst male observers. | Doe to the nature of the vignette, this study is only relevant for views concerning a female child victim and male perpetrator known to the victim. No data on respondent's educational or occupational status, which may be important. |
| Rohleder P. | 2010 | South Africa | 7 educators for young people with learning disabilities | Explore experiences of educators providing sex education for | Qualitative - interviews and focus group | The analysis reveals ambivalent feelings about providing sex education for people with disabilities, where on the one hand the | |

| | | | | people with learning disabilities in South Africa. | | need for sex education and the importance of them leading sexual lives is recognised, but there is some anxiety about the potential to cause harm or that providing sex education will lead to inappropriate sexual behaviour (like pre-marital sex and promiscuity). There is a need for support for the educators on how to deal with their dilemmas. | |
|---------------------------|------|-----------------|---|---|--|--|---|
| Rohleder P. | 2010 | South Africa | 110 organisations and 21 educators working with people with disabilities (all types) | Expore the risk issues for HIV for disabled people in South Africa. | Mixed methods - survey and interviews | People with disabilities are at perceived risk for HIV infection. Key risk factors are sexual abuse, lack of sexual education and disability stigma, which increased disabled people's vulnerability for engaging in unsafe sex. There is a need for studies incorporating the views of disabled people themselves. | Perspectives of DPOs and not necessarily of disabled people themselves. Response rate was low. |
| Rohleder P., Swartz L. | 2009 | South Africa | 7 educators for young people with learning disabilities | Explore the challenges faced by people involved in providing sex education for persons with learning disabilities. | Qualitative - interviews and focus group | None of the participants were strongly 'opposed' to providing sex education, and in fact stressed the importance of it. However, their interview narratives revealed some ambivalence about topics of sex and sexuality, for persons with learning disabilities. There appeared to be a tension between a 'human rights' discourse and a discourse of needing to restrict sexual expression. On the one hand there was a recognized human rights need to allow persons with learning disabilities to lead fully sexual lives, but there was also a more implicit need to control their sexual behaviours and sexual relationships, in relation to constructions around morality and what is regarded as appropriate, moral sexual behaviour. There is a complicated dilemma regarding sex education for persons with learning disabilities in the era of HIV/AIDS, and in the context of South | Small number of participants, in the context of one organisation. |

| Rohleder P., Swartz L., Schneider M., Eide A.H. | 2012 | South Africa | 34 schools and 21 educators for young people with disabilities (all types) | Explore the extent to which HIV education is reached to people with disabilities in South Africa, and the challenges faced by educators providing HIV prevention education to learners with disabilities. | Mixed methods - survey and interviews | Africa, where the prevalence of sexual abuse and rape is reportedly high. On the one hand, sex education and particularly HIV prevention education is essential. On the other hand, sex education may be used as an opportunity to discourage sexuality. We need to be concerned about HIV, and other sexually transmitted diseases, and so HIV prevention education is necessary. However, we need to be careful that it is not done in a way that demonizes and problematizes sex and sexuality without also finding ways to empower persons with learning disabilities to be permitted to have fulfilling, pleasurable sexual lives. Respondents recognise the importance of providing HIV prevention education for people with disabilities, but report some challenges in providing this education: barriers to communication; discomfort about issues of sexuality and disability; disagreements among staff about what is appropriate content for sexual health education; and fears of promoting sexual activity. There is no consensus among the informants as to what an HIV program should entail or how it should be held. There is a need for HIV prevention education to be specifically customized to the needs of the specific population. A general programme, which is included as part of a general curriculum and generally. There is need for more research on HIV education for youth with disabilities. Tailored to "mainstream" schools, would need to be adapted according to specific needs and disabling barriers faced. | |
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|--|------|-----------------|--|--|---|---|--|

| Roy M. | 2010 | UK | 9 women with intellectual disabilities (aged between 14 and 24 when first assessed for sterilization)) | The objectives of the case note audit were twofold. First, to determine if the assessment of capacity and best interests carried out 20 years ago disadvantaged the women. Second, to find out how the women had fared and whether the parental fear of pregnancy had been justified. | Qualitative - analysis of case notes | The 20 year follow-up showed that none of the women followed up had become pregnant or were using any contraception, demonstrating that the original risk assessment had been accurate. The assessment procedure that was adopted fits well with subsequent legislation and advice. The follow-up of our cohort shows that with appropriate care, women with intellectual disability can avoid unwanted pregnancy without recourse to radical surgery (sterilization). | There was some limitation to the case not with regards to the detail of the women's lives. |
|--|------|--------------|---|--|--|---|--|
| Rueda, H.A., Linton, K.F., Williams, L.R. | 2014 | USA | 13 high school social workers (working with adolescents with various disabilities) | Identify needs and challenges faced by high school social workers in supporting adolescents with disabilities toward dating and sexual health. | Qualitative - interviews | The social workers expressed a strong desire for school based comprehensive sexual education for all adolescents. Sex education received by adolescents was not modified to fit their needs, and may thus have limited effect on them. Social workers expressed the need for more training on how to educate youth with various types of disabilities. Social workers in this context work under an abstinence-only policy, which restricts their sexual education in general. They expressed a wish for more freedom in their communication with youth with regards to issues of sexuality. Findings highlight the widespread effects of multisystem policies and the pivotal role that school social workers may hold in advocating on behalf of reform. The findings also expound role demands and a lack of time and funding that limits social workers' ability to meet these demands. | The point of view of the adolescents themselves is not included. Small sample: explorative, but not generalizable. |
| Rusinga O. | 2012 | Zimbabw e | 50 deaf youth aged between 15-24 | Examine perceptions of deaf youth about their vulnerability to | Mixed methods - questionnaire and interviews | Deaf youth are sexually active and explorative, and thus vulnerable to sexual and reproductive health problems. Their | |

| | | | | sexual and reproductive health problems. | | perceptions are shaped primarily by sexual socialization rather than by their sensory conditions. The majority of the deaf youth are forming sexual relations amongst themselves. The government should adopt a human rights approach to the provision of sexual and reproductive health services to ensure universal access for all. | |
|--|------|-----------------|---|---|---|--|--|
| Saulo B., Walakira E., Darj E. | 2012 | Uganda | 16 individuals aged 17 to 46; 12 blind and 4 seeing health workers | To explore how blind people are reached by HIV-services in Kampala, Uganda. | Qualitative - interviews and focus groups | General knowledge on HIV prevention/transmission methods was good; however, there was scepticism about condom use. Blind people mainly relied on others for accessing HIV information, and a lack of special services for blind people to be able to test for HIV was expressed. The health service for blind people was considered inadequate, unequal and discriminatory, and harassment by healthcare staff was expressed, but not sexual abuse. Concerns about disclosure of personal medical information were revealed. There is a need for alternative, improved and adapted methods for sensitisation and voluntary counselling and testing for blind people. | Male interviewee may have influences female responses. |
| Schaafsma D., Stoffelen J.M.T., Kok G., Curfs L.M.G. | 2013 | Netherla nds | 11 programme developers of sex education programmes for people with intellectual disabilities | The aim of this study was to explore the development of sex education programmes targeted at people with intellectual disabilities. | Mixed methods - quantitative data and interviews | All programmes lack specific programme outcomes, do not have a theoretical basis, did not involve members of relevant groups in the development process and lack systematic evaluation, and are thus unlikely to be effective. Future programmes should be developed using a more systematic and theory- and evidence based approach. | Results reflect the views and memory of the program developers, and not the actual content of the program. |
| Seburg E.M., McMorris B.J., Garwick A.W., Scal P.B. | 2015 | USA | 557 individuals (287 with physical disabilities and 270 non-disabled) ages 16 to 24 | Examine the likelihood of discussing health- related behaviours with health care providers (HCPs), | Quantitative - questionnaires | Overall, we found low rates of discussions about the following topics: substance use, sexual and reproductive health, healthy eating, weight, and physical activity. Adolescents and young adults with MLs | |

| Shabalala, N., Jasson, A. | 2011 | South Africa | 54 individuals with Ids aged 11-35; 27 individuals with a known history of sexual abuse, and 27 individuals without a known history of sexual abuse. | comparing youth with and without mobility limitations (MLs). This study sought to investigate the presence of PTSD symptoms in a group of people with ID who had been sexually abused. | Quantitative - questionnaires | were less likely to report discussing substance use and sexual and reproductive health, but were more likely to discuss healthy eating, weight, and physical activity than peers without MLs. Those adolescents and young adults who reported substance use had higher odds of discussing this topic and those who reported having sexual intercourse had higher odds of discussing sexual and reproductive health. The study confirms the need to develop and implement strategies to improve counselling in clinical settings, especially for youth with MLs. Adolescents and young adults with MLs have higher rates of health care utilization than peers without disabilities, and HCPs have the opportunity to play a critical role in health promotion efforts. Higher rates of a PTSD diagnosis and a higher intensity of PTSD symptoms were found in the group with than in the group without a history of sexual abuse. There were no significant differences between self and care-giver reports with respect to the prevalence of a PTSD diagnosis, but there were differences on the different symptom clusters. The results indicate that survivors with ID should be asked directly about their internal subiective ovneriences with care | Small sample. Limited to PTSD, and other symptoms of trauma were excluded. |
|---------------------------------------|------|-----------------|--|---|----------------------------------|--|--|
| | | | | | | internal subjective experiences, with care- giver reports being used as collateral information, and that therapeutic interventions following sexual abuse should be offered. | |
| Shah P., Norlin C., Logsdon V., | 2005 | USA | 136 gynecologic clinicians (about care for | The goal of this study was to assess the barriers to gynecologic | Quantitative - questionnaires | The comfort level among surveyed clinicians in providing gynecological care to disabled adolescents was relatively low, | |

| Samson- Fang L. | | | adolescents with disabilities) | care for adolescents with disability in this state. | | even for routine screening. Respondents identified the following as barriers to providing this care: time, reimbursement, inadequate knowledge, and disability- related issues (office access and preference to not serve this population). Suggested solutions included: continuing education programs, consultation to practices on serving both youth and individuals with disability, and better billing mechanisms. | |
|--|------|-----|---|--|----------------------------------|---|--|
| Shandra CL, Chowdhury AR. | 2012 | USA | 2729 adolescent and young adult females ages 12-24 with and without disabilities (all types) | This article examines the association between disability and type of first sexual relationship, degree of discussion about birth control, and pregnancy wantedness. | Quantitative - questionnaires | An important result is that we find a marked bifurcation in the types of relationships that girls with mild disabilities have with their first sexual partner. Results suggest that having a mild disability increases the likelihood of having first sexual intercourse with a stranger versus a steady dating partner. Results also suggest that having a mild disability or a learning or emotional condition also increases the likelihood of having first sexual intercourse in a highly committed relationship versus with a steady dating partner. Another important finding is that girls with multiple conditions or serious disabilities who do not use contraception at first sexual intercourse are also much more likely to want a pregnancy than their counterparts without disabilities. Girls with multiple or seriously limiting conditions are also more likely not to think about pregnancy than to not want a pregnancy, when compared to girls without disabilities. | |
| Shandra, C.L., Hogan, D.P., Short, S.E. | 2014 | USA | 10782 women aged 15-44 with and without disabilities (all types) | Examine attitudes toward motherhood and fertility intentions among women with disabilities. | Quantitative - questionnaires | Women with and without disabilities held similar attitudes toward motherhood. Among women without children, women with and without disabilities were equally likely to want a child and equally likely to | The disability measure used in the survey is crude; it does not include any information that permits distinctions by the type or severity of |

| | | | | | | intend to have one. However, childless women with disabilities who wanted and intended to have a child were more likely to report uncertainty about those intentions than were childless women without disabilities. Mothers with disabilities were more likely to want another child, but less likely to intend to have a child, than were mothers without disabilities. | disability. Only women who could participate without assistance were included. |
|---|------|--------|---|--|---|--|--|
| Shoshan L., Ben-Zvi D., Meyer S., Katz-Leurer M. | 2012 | Israel | 25 people (17 female) with physical disabilities aged 16-35 | To describe the basic knowledge of body anatomy and functioning, and the sexual knowledge of young adults with spina bifida (SB) and to investigate the associations between independence in daily functions and communication skills on the one hand and sexual knowledge and activity on the other among young people with SB. | Quantitative - questionnaires | Young adults with SB who live in Israel exhibit a relatively low level of sexual experience. All of the informants were exposed to some form of sex education, but their actual knowledge of body anatomy and functions and sexual knowledge was found lacking. More than 80% of the participants lived with their parents. The known relationship between independence and sexual experience was also found in this study. A positive association was noted between knowledge of body anatomy and function, and having sexual relationships, stressing the importance and relevance of sex education for children with SB. | May be a biased sample: all participants were recruited from SB multidisciplinary follow-up clinic. |
| Soylu N., Alpaslan A.H., Ayaz M., Esenyel S., Oruç M. | 2013 | Turkey | 256 cases of child sexual abuse - children aged 6 to 16 (102 children with intellectual disability, and 154 non-disabled) | The purpose of this study was to compare sexually abused children and adolescents, with and without intellectual disabilities (ID), in terms of post-abuse psychiatric disorders, features of the sexual abuse, and | Quantitative - analysis of case report data | It was stated that girls and boys in the general population were exposed to abuse at an equal rate; however, boys had a higher rate of physical abuse and girls had a higher rate of sexual abuse. Results of this study demonstrate that there are important differences between the cases with and without ID in terms of the type of sexual abuse. Sexual abuse types involving sexual contact and penetration were encountered at higher rates in cases with ID. It was determined that in the group with | Psychiatric diagnosis were not made with structured evaluations. |

| Spencer N., Devereux E., Wallace A., Sundrum R., Shenoy M., Bacchus C., Logan S. | 2005 | UK | 119729 infants born between January 1983 and December 2001. (including infants with various types of disabilities) | sociodemographic characteristics. | Quantitative - analysis of national population data | ID, sexual abuse types including penetration and contact had higher rates, they were exposed to more frequent repeated abuses, the abuses were revealed with their own reports at a later period and lower rates, and post-abuse pregnancies were more frequent. It was also determined that the abuser was a familiar person and a family member at lower rates and more than one abuser was encountered more frequently, compared to the group without ID. While no difference was determined between the two groups in terms of the frequency of post-abuse post- traumatic stress disorder (PTSD) and major depressive disorder (MDD), conduct disorder (CD) was observed more frequently in the group with ID. Children with disabling conditions seem to be at increased risk of registration for child abuse and neglect. The pattern differs with specific disabling conditions; Cerebral palsy, language and speech disorders, learning difficulties, conduct disorders were all associated with increased risk of registration for child abuse and neglect. | Strength: population based. |
|--|------|--------|--|---|--|--|---|
| Stewart C.C. | 2012 | Canada | 4 mothers of children with developmental disabilities | Examine the experiences of mothers of children with developmental disabilities who were sexually abused. | Qualitative - interviews | The abuse increased what was already a significant burden of care and further reinforced stigmatization, marginalization, and powerlessness. At the same time, the study painted a picture of committed and determined mothers who were devoted to their children and Individual professionals went out of their way to try to help. | Limited sample. |
| Stewart C.C. | 2009 | Canada | Children with intellectual disabilities, their | To explore how sexual abuse victims with intellectual disabilities, | Qualitative - interviews | The sexual abuse victims, their families and relevant professionals are ill-prepared to cope with the complexities of sexual abuse | Multiple perspectives explored. ONLY ABSTRACT AVAILABLE |

| | | | families and professional staff | their families and relevant professionals deal with sexual abuse issues. | | and intellectual disability. A significant barrier is the lack of communication and sharing of expertise between the various child-protection systems. As a result of this compartmentalization of expertise, a full understanding of the sexual abuse experience is not gained, and the response is inadequate. | |
|--|------|-----------|---|--|---|--|--|
| Stokes, M.A., Kaur, A. | 2005 | Australia | 23 parents of adolescents with high functioning autism (and 50 parents of non- disabled adolescents). | To compare sexual behaviours among adolescents with high- functioning autism (HFA) and typical populations, and indicate whether specialized education is required. | Quantitative - questionnaire | Results from this study support the hypotheses when compared with typical adolescents, adolescents with HFA would (1) display poorer social behaviours; (2) engage in fewer behaviours related to privacy and have poorer knowledge regarding privacy issues; (3) have less sex education; and (4) display more inappropriate sexual behaviours; and that (5) parental concerns would be greater for the HFA sample. | |
| Suter S., McCracken W., Calam R. | 2009 | UK | 61 teachers of students who are deaf | Explore the views of teachers of the deaf on the growth of sexual understanding in deaf children, as well as to provide an insight into the challenges these professionals face in the area of sex education. | Quantitative - questionnaire | The study's findings highlight an overall concern over the suitability of current methods and materials often used to teach mainstreamed deaf children about sexuality and relationships. The data show a demand for a sex education module for teachers of the deaf and a need for deaf-friendly sex education material. | Small sample size. |
| Suter, S., McCracken, W., Calam, R. | 2012 | UK | 27 deaf (14 females) and 54 hearing young people ages 16-25 | The purpose of this survey study was to explore the views of young deaf and hearing people (16–25 years old) on school and home sex and relationships education (SRE). | Quantitative - survey questionnaire | Overall, deaf participants indicated greater levels of satisfaction with school SRE than hearing respondents. More deaf young people than young hearing people felt that the school had provided them with enough opportunities to learn about sexuality and relationships. The deaf group showed a preference for school SRE lessons to start at a later age than the hearing group. Mothers | Due to difficulty recruiting respondents for the deaf sample, a convenience sampling method was used, and thus the deaf population may not be representative. |

| | | | | | | and friends were the two sources most frequently consulted in both groups. Teachers and school nurses were a third source frequently used by the deaf group. The views of deaf and hearing youth on their own SRE are important for the development, implementation and delivery of the school SRE curriculum. | |
|----------------------|------|-----|---|--|----------------------------------|--|--------------------|
| Swango- Wilson A. | 2008 | USA | 85 caregivers of individuals with intellectual disabilities and developmental disabilities | This study explores the relationship of caregiver perception of sexuality of individuals with intellectual and developmental disabilities, the caregiver perception of agency support for sex education, and their perception of their ability to participate in a sex education program designed specifically for individuals with intellectual and developmental disabilities. | Quantitative - questionnaires | The findings from this study support the need to provide information and support to caregivers as they attempt to participate in sex education programs designed for people with ID. Specific areas of sensitivity toward caregiver needs are safe sex and same sex partner issues. | |
| Swango- Wilson A. | 2011 | USA | 3 individuals with intellectual/develo pmental disabilities | The purpose of this study was a qualitative inquiry to identify what individuals with ID/DD expect from a sex education program. | Qualitative - interviews | Data emerged for the future focus of sex education programs to include: friendship, relationships, and safe sex behaviours. Recommendations for sex education include: (1) Mix gender classes; (2) Classes that focus on practical ways to develop relationships; (3) Inclusion of class section for caregivers separate from class for ID/DD participant; (4) Practice skills in different settings (homework); (5) Continue to give | Small sample size. |

| | | | | | | information of safe sex practices but don't make that the main focus: and (6) Include information on how to safely report abuse from care givers. | |
|--|------|----------------------------------|---|--|---|--|--|
| Tanabe M., Nagujjah Y., Rimal N., Bukania F., Krause S. | 2015 | Kenya, Nepal and Uganda | 287 refugees with disabilities (185 girls and women) ages 15-59 and 65 caregivers and family members | Explore the risks, needs, and barriers for refugees with disabilities to access SRH services, and the practical ways in which these challenges could be addressed. | Qualitative - interviews and focus groups | Findings showed that refugees with disabilities demonstrated varying degrees of awareness around SRH, especially regarding the reproductive anatomy, family planning, and sexually transmitted infections. Among barriers to accessing services, lack of respect by providers was reported as the most hurtful. Pregnant women with disabilities were often discriminated against by providers and scolded by caregivers for becoming pregnant and bearing children; marital status was a large factor that determined if a pregnancy was accepted. Risks of sexual violence prevailed across sites, especially for persons with intellectual impairments. The ability of women with disabilities to exercise their SRH rights was mixed. Refugees with disabilities showed a mixed understanding of their own rights in relationships and in the pursuit of opportunities. Findings speak to the need to realize the SRH rights of refugees with disabilities and build their longer-term SRH capacities. | Not all ages and impairments were adequately represented. |
| Thompson V.R., Stancliffe R.J., Broom A., Wilson N.J. | 2016 | Australia | 23 clinicians working with people with intellectual disabilities | Several assessment tools have been developed to assess the sexual knowledge of people with intellectual disability. This paper examines how clinicians' are using these tools. | Qualitative - interviews | Assessment of sexual knowledge is not routine in disability service provision. Sexual knowledge is typically only assessed when there has been an incident of problematic sexualised behaviour. This reactive approach perpetuates a pathological sexual health discourse. Clinicians using assessment tools said that they need the tools to support work they | Small, but diverse sample. |

| | | | | | | do in relation to sexual health of people with intellectual disability. They also reported that the tools have gaps and are not fully meeting their needs or the needs of people with intellectual disability. | |
|--|------|-----------|--|--|----------------------------------|---|---|
| Thompson V.R., Stancliffe R.J., Wilson N.J., Broom A. | 2016 | Australia | 23 clinicians working with people with intellectual disabilities | Several assessment tools have been developed to assess the sexual knowledge of people with intellectual disability. This paper examines clinicians' perspective on the usefulness and usability of these tools. | Qualitative - interviews | Several themes emerged from the interview data; (a) clinicians want to use sexual knowledge assessment tools to support their work, (b) clinicians want more guidance in relation to administering these tools, and (c) clinicians have concerns about the usefulness and usability of sexual knowledge assessment tools. | Small, but diverse sample. |
| Titus JC. | 2010 | USA | 111 youth (42% female) who are deaf or hard-of- hearing and a matched comparison sample of hearing youth | The article profiles the prevalence, severity, and characteristics of victimization among a group of youths with hearing loss presenting to substance abuse treatment. | Quantitative - questionnaire | The hearing loss group reported more widespread, more severe abuse than that reported by their hearing peers. Physical abuse and weapon attacks were significantly more prevalent among the deaf and hard of hearing youths. No differences in sexual or emotional abuse were observed. Youths with hearing loss also reported increased rates of abuse by a trusted person and abuse that made them fear for their lives. | Not investigated on gender differences due to power restrictions. |
| Tobin-West, C., Akani, Y. | 2014 | Nigeria | 219 adolescents with hearing disabilities (51.6% female) and 203 non-disabled adolescents | This paper examines the disparities in information about the human immuno- deficiency virus (HIV) infection among hearing and hearing- impaired adolescents in Port Harcourt, Nigeria. | Quantitative - questionnaires | Awareness about HIV was significantly lower among hearing-impaired adolescents. Most of them did not even know how HIV was transmitted, while many believed that HIV was transmitted through mosquito bites or by eating together or sharing utensils. Only a few understood that unprotected sex was a major risk factor for HIV transmission. Similarly, most of them did not know how HIV could be prevented. Their HIV risk perception for was equally low as only a third had ever tested for HIV | |

| Kett M., Bah O., Morlai T., | | | 189 (53.9% female) with disabilities (all types) | care services between disabled and non- disabled men and | questionnunes | health care services than non-disabled people after adjustment for other socioeconomic characteristics (bivariate | |
|--|------|-----------------|---|--|---------------------------------------|---|--|
| Trani JF., Browne J., | 2011 | Sierra Leone | 423 individuals ages 18 and over. | Compare health status and access to health | Quantitative - questionnaires | As expected, we showed that people with severe disabilities had less access to public | |
| Touko A, Mboua CP, Tohmuntain PM, Perrot AB. | 2010 | Cameroo n | 118 (49.2% female) deaf and hearing impaired individuals ages 15 to 34. | intellectual disabilities. Examine sexual behaviour of a target group of hearing impaired persons in Yaounde, the capital city of the Republic of Cameroon, through the measurement of their HIV prevalence to enable assessment of their sexual vulnerability and to help reduce the gap in existing HIV serology data among people with disabilities in general and the deaf. | Quantitative - questionnaires | knowledge, that is sexual knowledge. The hearing impaired were highly involved in risky sexual practices, as observed through major sexual indicators, such as: age at first sexual intercourse; condom use; and knowledge of sexually transmitted infections and AIDS. Furthermore, it was noted that the HIV prevalence rate of the hearing impaired in the capital of Cameroon was 4%, close to the prevalence in the city's general population (4.7%). | |
| Todd S. | 2009 | UK | school for learners with severe intellectual disabilities | This article reports on an ethnographic and sociological study of the curriculum inside a special school for students with severe | Qualitative - ethnography study | compared to two-thirds of their hearing counterparts. The results of the study suggests that significant differences in HIV information and knowledge exists between hearing and hearing-impaired adolescents in Nigeria. The gap is attributed to lack of sexuality and HIV-specific education for adolescents with disabilities, thus unduly exposing them to avoidable HIV risk. The data suggest that two codes were in operation within the curriculum. The first was designed to draw the out-of-school experiences of students into the classroom for greater scrutiny. The second involved the strict regulation of 'dangerous' | |

| Bailey N., Groce N. | | | | women in urban and peri-urban areas of Sierra Leone, paying particular attention to access to reproductive health care services and maternal health care for disabled women. | | modelling). However, there were no significant differences in reporting use of contraception between disabled and non- disabled people; contrary to expectations, women with disabilities were as likely to report access to maternal health care services as did non-disabled women. Rather than disability, it is socioeconomic inequality that governs access to such services. We also found that disabled women were as likely as non-disabled women to report having children and to desiring another child: they are not only sexually active, but also need access to reproductive health services. | |
|---|------|-----|--|--|---|---|--|
| Treacy V., Randle J. | 2004 | UK | 8 student nurses (about the sexuality of children with learning disabilities) | Explore pre- registration nursing students' knowledge and attitudes towards the sexuality of children with special needs. | Qualitative - interviews | Participants felt comfortable defining sexuality, but addressing sexuality was hampered in practice. Specific issues that were raised were: consent, parental choices and abuse of children. Respondents felt that they needed more education and training on these issues. | |
| Turner, H., Vandermind en, J., Finkelhor, D., Hamby, S., Shattuck, A. | 2011 | USA | 4046 children ages 2-17 (48.9% female). 16.9% had a disability (physical, intellectual or behavioural) | Examines the associations between several different types of disability and past- year exposure to multiple forms of child victimization. | Quantitative - cross-sectional survey | Results suggest that attention-deficit disorder/attention-deficit with hyperactivity disorder elevates the risk for peer victimization and property crime, internalizing psychological disorders increase risk for both child maltreatment and sexual victimization, and developmental/learning disorders heighten risk only for property crime. In contrast, physical disability did not increase the risk for any type of victimization once confounding factors and co-occurring disabilities were controlled. It appears that disabilities associated with interpersonal and behavioural difficulties are most strongly associated with victimization risks. | Disability assessed by diagnosis type; may miss information about particular symptoms of problems that create risk for victimization. Children with more severe disabilities are underrepresented in the sample. Not possible to determine the causal direction of the association between disability and victimization. |

| Umoren, A.M., Adejumo, A.O. | 2014 | Nigeria | 181 (42% female) youth with disabilities (physical, hearing or visual) ages 16- 25. and comparison group of 181 non- disabled youth | Investigate the role of sexual attitude and sexual risk-behaviour in the perception of HIV vulnerability and differences among youths with disability and able-bodied youths. | Quantitative - cross-sectional survey | The findings disprove the misconception that people with disability are asexual. The study also established some similarities and differences among YWD and youth without disabilities. Sexual risk behaviour is related and has influence on perceived HIV- vulnerability in both groups, while sexual attitude did not. Youths with disability who have liberal sexual attitude and high score in sexual risk behaviour reported the highest perceived HIV-vulnerability. Visually-impaired participants perceived a higher level of HIV-vulnerability compared to the hearing and physically impaired. | |
|---|------|-----------------|--|---|---|--|--|
| van der Put C.E., Asscher J.J., Wissink I.B., Stams G.J.J.M. | 2014 | Netherla nds | 102 juvenile offenders (21% girls) with intellectual disabilities, and 526 non-disabled. | To examine differences between juvenile offenders with and without ID in the relationship between maltreatment victimisation and sexual and violent offending. | Quantitative - questionnaire | Seventy per cent of the juvenile offenders with ID and 42% of the juvenile offenders without ID had experienced abuse and/or neglect. Both sexual and violent offending were more common in juvenile offenders with ID than in juvenile offenders without ID. Moreover, the relationship between different forms of maltreatment and sexual offending was stronger in juvenile offenders with ID than in juvenile offenders without ID. | Only included people with IDs who had a diagnosis, and thus there could be people in the control group who had ID, but no formal diagnosis. |
| van der Stege H.A., Hilberink S.R., Bakker E., van Staa A.L. | 2016 | Netherla nds | 154 professionals working with young people with physical disabilities and chronic conditions | The aim of the study was to gain insight into use of a new board game (SeCZ TaLK) to facilitate discussing sexual health with adolescents with chronic conditions in healthcare and special education, and to establish impeding and facilitating factors for using the game. | Quantitative - questionnaire | Results showed that the actual use of SeCZ TaLK was associated with a positive attitude towards discussing sexuality, a high perceived feasibility of the game, own motivation and skills, and correspondence with work routines. The presence of preconditions (such as time to play and staffing capacity), participant's recruitment for game sessions and the professional environment were non-significant factors. Professionals appreciated the board game SeCZ TaLK but actual use depended on own motivation and skills and correspondence | The responsible professionals are probably above average interested in and concerned with these issues. However; professionals from several hundred organisations were involved. They may therefore not be representative of professionals working with adolescents with chronic conditions. |

| Van der Stege H.A., Hilberink S.R., Visser A.P., Van Staa A.L. | 2014 | Netherla nds | 336 professionals working with young people with physical disabilities and chronic conditions | The objective of this study was to identify determinants of professionals' intention to use the new board game SeCZ TaLK to facilitate sexual health discussions with young people with chronic health conditions and disabilities, and to gauge whether intention led to actual use. | Quantitative - questionnaire | with work routines. To enhance the use of the board game, management should prioritize discussing sexuality and support the professionals in developing relevant skills. Professionals with higher self-efficacy and more experience in discussing sexual health were more likely to intend to use the game. At follow-up, intention to use explained 21% of the variance in actual use. SeCZ TaLK fits easily into the daily practice of professionals working in assisted living and day-care facilities; other professionals experienced greater difficulty integrating the game into their practice. Despite this, SeCZ TaLk was also used across a wide range of settings including in psycho- educational groups, group consultations in hospitals and group therapy in rehabilitation centres. Professionals appreciated the board game SeCZ TaLK, but actual use depended on their own motivation and skills and compatibility with work routines. | The responsible professionals are probably above average interested in and concerned with these issues. However; professionals from several hundred organisations were involved. They may therefore not be representative of professionals working with adolescents with chronic conditions. |
|---|------|-----------------|--|---|---------------------------------|--|---|
| van der Stege H.A., van Staa A., Hilberink S.R., Visser A.P. | 2010 | Netherla nds | 85 adolescents and young people (54.1% female) ages 11 to 24 with physical disabilities and chronic conditions | Evaluate the feasibility and appreciation of a new educational board game (SeCZ TaLK) that stimulates communication on sexuality and intimate relationships in youth with chronic conditions. | Quantitative - questionnaire | An educational board game like SeCZ TaLK is a promising tool to encourage discussion about sexuality and intimate relations with adolescents with chronic conditions and disabilities. This game is appreciated by both sexes, slightly more by girls, and is useful for a broad age range, but more popular among the youngest of the sample than the older in the sample. It proved to be useful in different settings (including special schools, outpatient clinics and patient organizations) with various patient groups. Adolescents found discussing | Tested only on a small sample, and the responsible professionals are probably above average interested in and concerned with these issues. However; professionals from several hundred organisations were involved. Not an effectiveness study, and can only say something about subjective beliefs and experiences, and not about real effect. |

| Wazakili, M., Mpofu, R., Devlieger, P. | 2006 | South Africa | 10 parents and 10 young people ages 15-24 with physical disabilities | This study explored the experiences and perceptions of sexuality and HIV/ AIDS | Qualitative - interviews | The results indicate that disabled young people have limited factual knowledge about sexuality and HIV/AIDS. The decisions and choices they make about sexual | Only focused on a small number of people with physical disability, in only one geographical location. People living in remote areas with |
|--|------|-----------------|---|---|--|---|---|
| Wazakili, M., Mpofu, R., Devlieger, P. | 2009 | South Africa | 16 young (10 females) people with physical disabilities ages 15- 24 | The purpose of this study was to record the voices of disabled young people regarding their experiences of sexuality and HIV and AIDS and to determine the role of rehabilitation professionals in this regard. | Qualitative - interviews | The results indicated that most participants had received some form of rehabilitation for their physical impairment, yet sexuality and HIV/ AIDS matters were not part of the rehabilitation process. Although the majority were aware of sexuality and HIV/ AIDS issues, their limited factual knowledge did not persuade them to change their sexual behaviour or take preventive measures against contracting HIV infection. Thus, rehabilitation professionals need to widen their scope of practice to include the promotion of good sexual and reproductive health for disabled young people. | Only focused on a small number of people with physical disability, in only one geographical location. People living in remote areas with particularly high levels of crime were not reached in this study. |
| van Schrojenstei n Lantman- de Valk HM, Rook F, Maaskant MA. | 2011 | Netherla nds | 234 women with intellectual disabilities ages 15- 59 | The study aims to determine the use (number and method) of contraception by women with intellectual disabilities (ID), the indications, sources of referrals and relations with level of ID and age of the women concerned. | quantitative - analysis of medical file data | sexuality and intimate relations important and most felt that SeCZ TaLK enabled this. Almost all participants felt free to express their opinion during the game and thought it was fun to play. Professionals in health care and education also liked the game and would recommend it to their colleagues. Almost half of the women used some method of contraception. 78% used pharmacological contraceptive methods, 20% underwent surgical contraception and 2% used both. Main reasons for contraception were problems with menstruation, behaviour and/or prevention of pregnancy. Requests for contraception were initiated mainly by physicians and parents. The participants used less contraception than the general population. | |

| | | | | disabilities in a South African Township characterised by high unemployment rates and lack of social services. | | situation in Nyanga. Their need to be loved and accepted, need for job security and family life, were more important than practicing 'safe sex'. Therefore, there is need for HIV/AIDS programme developers to take into account the experiences and perceptions of the target population. | crime were not reached in this study. |
|--|------|-----------------|--|--|--|--|--|
| Wells M., Mitchell K.J. | 2014 | USA | 1560 adolescents (50% female) ages 10-17. 11% had learning disabilities, 6% had physical disabilities and 2% had both learning and physical disabilities | Explore Internet use patterns and risk of online victimization between youth with and without two specific types of disabilities. | Quantitative - cross-sectional survey | Youth receiving special education services in schools were more likely to report receiving an online interpersonal victimization in the past year, even after adjusting for other explanatory factors. | Cross-sectional data, and thus causal inferences cannot be made. Analysis relies on parental report of disability. |
| Wiegerink DJ, Roebroeck ME, van der Slot WM, Stam HJ, Cohen- Kettenis PT; South West Netherlands Transition Research Group | 2010 | Netherla nds | 87 young people (36 female) with cerebral palsy ages 18-22 | The aim of this study was to describe the peer group activities, romantic relationships, and sexual activity and their interrelations of young adults with cerebral palsy (CP). | Quantitative - questionnaires and structured interviews | The study cohort reported having friends and participating in activities with peers; 71% had experience of dating, 23% had a current romantic relationship, and 38% had experience of intercourse. Young adults with CP had less experience in romantic and sexual relationships than an age- appropriate Dutch reference population. Peer group activities and dating favoured development of romantic relationships and sexual activity. Older age was associated with greater sexual activity. Motor functioning, education level, and gender did not correlate with romantic relationships or sexual activity. | Despite multicultural population of research area, participants were primarily white and of Dutch-origin. |
| Wiegerink DJ, Stam HJ, Gorter JW, Cohen- Kettenis PT, Roebroeck ME; | 2010 | Netherla nds | 103 young people (42 female) with cerebral palsy ages 16-20 | To describe the development of romantic relationships and sexual activity of young adults with cerebral palsy (CP), to investigate whether | Quantitative - questionnaires and structured interviews | We observed a significant increase in dating in young adults with CP during the 4-year period; however, the experience in romantic relationships did not increase largely during this period. Young adults with a lower education level began dating later than those with higher levels. Significantly | Despite multicultural population of research area, participants were primarily white and of Dutch-origin, and the sample of individuals with alternative sexual |

| Transition Research Group Southwest Netherlands. | | | | this development is associated with demographic and physical characteristics, and to compare the sexual activity of this group with an age- appropriate Dutch reference population. | | more women were in current romantic relationships than men. During the 4 years, participants' sexual experience increased significantly for all sexual milestones evaluated. Level of gross motor function was associated significantly with intercourse experience. Compared with an age-appropriate Dutch reference population, young adults with CP participated at a lower level in romantic relationships and sexual activities, but had equal sexual interest at the final assessment. | pretences (LGBT) was too small to analyse separately. |
|--|------|---------|---|--|---|---|--|
| Wienholz S., Seidel A., Michel M., Haeussler- Sczepan M., Riedel-Heller S.G. | 2016 | Germany | 140 students (54 female) with physical, visual and hearing disabilities ages 12-18. And 306 non-disabled students | Explore sexual experiences of adolescents with and without disabilities. | Quantitative - cross-sectional survey | 28% of teenagers with disabilities reported experiences with intercourse. Among those, there were more often males and teens with hearing impairments. 39% of adolescents without disabilities had experiences with intercourse, and among them were more female adolescents. Despite being less sexually active teenagers with disabilities experienced earlier first sexual intercourse than age-mates without disabilities. Thirty-six percent of all adolescents were in a stable relationship and among them teenagers with disabilities had experiences with intercourse less frequently. Predictors of sexual intercourse were increasing age, no disability, and a stable relationship. Readiness to talk about sexuality played a minor part. | Biased sample of disabled students from special education schools, not from integrated schools. |
| Wienholz, S., Seidel, A., Schiller, C., Michel, M., Häußler- Sczepan, M., | 2013 | Germany | 140 students (54 female) with physical, visual and hearing disabilities ages 12-18. And 306 non-disabled students | To compare the sexual knowledge and experiences of adolescents with disabilities with non- disabled peers. | Quantitative - cross-sectional survey | Fewer adolescents with disabilities reported thinking that they had adequate sexual knowledge. 28% of adolescents with disabilities reported having had sex compared to 39% of non-disabled. Adolescents with disabilities made less use of condoms during sex. | ONLY ABSTRACT AVAILABLE |

| Riedel- Heller, S.G. | | | | | | | |
|---|------|-----|---|---|---|---|---|
| Wilkenfeld, B. F. Ballan, M.S. | 2011 | USA | 10 educators of young people with developmental disabilities | Explore educators' attitudes and beliefs towards the sexuality of adolescents and adults with developmental disabilities. | Qualitative - interviews | Results indicate that educators hold a positive view towards providing sexuality education and access to sexual expression for persons with developmental disabilities. Educators viewed sexuality as a basic human right, yet expressed concerns regarding capacity to consent to and facilitation of sexual activity. Educators also expressed a lack of clarity defining role and responsibilities as a sexuality educator and apprehension about providing sexuality education. But overall attitudes were positive. | Small sample size. |
| Wilkinson, V.J., Theodore, K., Raczka, R. | 2015 | UK | 4 young people (2 females) ages 19-22 and their carers | Explore the experiences of young people with IDs and their carers' with regards to the development of sexual identity alongside the ID identity. | Qualitative - interviews | Young people struggled for an 'as normal as possible' adult identity, and to develop sexual identity as a 'normal' identity, in the context of the overshadowing ID identity. Despite believing they should be enabled to develop sexual identity as part of their transition to adulthood, young people faced many obstacles, including stigma related to their ID. Carers described their challenges in proactively supporting sexual identity education and exploration, due to concerns about risk. Equality and protection need not be either/or priorities. | Small sample. Communication with individuals with ID was challenging, but were supported by interviews with their carers. |
| Williams F., Scott G., McKechanie A. | 2014 | UK | 34 young people with intellectual disabilities ages 16- 35 | Explore views and experiences of younger adults with intellectual disability with regards to sexual health services and support. | mixed method - structured interview | Developing sexual health services to encourage people with ID to use them is a challenge because their preferences vary greatly. It is important to meet their needs by continuing to provide a variety of services like those offered by GPs, genitourinary medicine clinics, well woman clinics, and young people's services. Most participants wanted to attend mainstream services and felt staff from these services | Small sample size due to difficulties recruiting this population. Used opportunistic sampling |

| Willis, R.G., Vernon, M | 2002 | USA | 58 deaf youth and 168 non-disabled youth | Study of characteristics of emotional disturbance in deaf youth compared to a hearing sample at a treatment facility for youth with serious psychological disturbances. | Qualitative - descriptive data | should be able to meet their special needs. This study emphasised the need for involving younger adults with ID in the planning and commissioning of new services and review of current services. The findings show abnormally high rates of sexual abuse for both deaf and hearing young people admitted to residential treatment. One hundred percent of the deaf children had experienced sexual abuse based on their admitting information. The hearing children and adolescents were both 20 percentage points below their deaf peers in their rates of reported sexual abuse rates. | |
|-------------------------------|------|-----------|--|--|--|---|---|
| Wilson HW, Donenberg G. | 2004 | Australia | 30 adolescents (53% female) ages 13-19 with psychiatric disabilities and their primary caregiver | This pilot study investigated the relationship between parent communication about sex and sexual risk-taking among treatment-seeking adolescents in psychiatric care from the perspective of adolescents and their parents. | Quantitative - coded analysis of video- recorded conversations | Quality but not frequency of parent-teen communication was associated with adolescent sexual risk-taking, and ethnic differences in communication were found. Findings suggest that the way parents of troubled youth discuss sex, birth control, and HIV is more related to their teens' sexual behaviour than how often they have such discussions. these data suggest that programs designed to reduce sexual risk- taking among youth in psychiatric treatment may be more effective if they include teaching parents how to talk to their teens about sex, rather than merely encouraging such communication. Furthermore, findings suggest that increased parental control and direction may protect troubled urban youth from engaging in risky sexual behaviour. Results of this study revealed ethnic differences in parents' communication about sex, highlighting the need to be aware of | Limited sample, small-scale study, preliminary nature, and thus not conclusive. |

| | | | | | | cultural and racial differences in strategies and programs. | |
|--|------|-------------------------|---|--|--|---|--|
| Wilson N.J., Frawley P. | 2016 | Australia | 17 staff working with young people with intellectual and developmental disabilities | Explored if and how sex education and support is offered by transition staff to young people with intellectual and developmental disability transitioning to adulthood. | Qualitative - focus groups | A key theme was that staff are "reluctant counsellors." Although staff provided social and sexual education, they reported being underprepared and relied primarily on their own values as guidance. They did this in full recognition that transition services filled a social gap for participants, blurring the lines between education and social support. | Only one geographical location and only one program. Only includes youth with mild and moderate IDD, not severe. |
| Yıldız, G. Cavkaytar, A. | 2017 | Turkey | 44 mothers of young adult children with intellectual disabilities | The purpose of the present study was to scrutinize the effect of a Sexuality Education Program for Mothers of Young Adults with Intellectual Disabilities (SEPID) on the attitudes of mothers toward the sexuality education of their children and their perceptions of social support. | Quantitative - pre- and post- intervention questionnaires | Findings demonstrated that SEPID changed the attitudes of mothers toward the sexuality education of their children in a positive direction and improved their perceptions of social support. Social validity findings showed that the mothers were satisfied with the program. | Limited sample, not representative. |
| Yousafzai AK, Edwards K, D'Allesandro C, Lindström L. | 2005 | Rwanda and Uganda | 23 Adolescents with disabilities (physical, visual, hearing, learning and communication), and parents | The study had 2 aims: (1) To explore whether knowledge about HIV and AIDS was similar among adolescents with disabilities compared with their non-disabled peers; and (2) To determine factors which may increase vulnerability of disabled adolescents to HIV infection and/or | Qualitative - interviews and focus groups | Barriers preventing adequate access to information about HIV and AIDS experienced by adolescents with disabilities depended on the nature and severity of the impairment. For example, parents and health workers were unable to communicate with deaf adolescents using sign language, adolescents with physical impairments were often unable to access community meetings about HIV and print material was not adapted for those with visual impairments. Further, assumptions by health workers and community | |

| | | | | inappropriate access to HIV related services. | | members that people with disabilities were not sexually active lead to the marginalisation of disabled people from HIV services. Adolescents with disability described low self-esteem and issues of self-efficacy affecting control of safer sexual relationships. A high level of targeted abuse, rape and exploitation was reported leading to vulnerability among this population. | |
|--------------------------|------|----------------|---|---|---|---|--|
| Yun I, Jung S, Yoo J. | 2015 | South Korea | 7520 adolescents.162 with physical disabilities and 420 with learning disabilities | This study examines the association between disability and violent victimization across a time span ranging from adolescence to young adulthood while controlling for self- involvement in delinquent/criminal behaviours. | Quantitative - longitudinal survey data | This study's results highlight the heightened risk of violent victimization to which people with learning disabilities may be exposed throughout their life span. The results show that although physical disability is not linked to victimization risk, learning disability is significantly associated with an elevated risk of violent victimization. | Excludes adolescents with disabilities in special schools. Learning disability was identified through parents' reports, and not diagnosis. |
| Zaviršek D. | 2002 | Slovenia | 25 individuals with disabilities (all types) | This article presents personal testimonies of women with different disabilities who have been abused. It discusses the responses of professionals and caregivers, who tend to minimise the importance of abuse against disabled people. | Qualitative - interviews | Based on the results, the article claims that ignoring the memories of sexual abuse is part of a subtle and unintentional discrimination, which reflects a continuity of prejudices and hatred toward disabled children and adults in the private realm as well as in public care. | |

APPENDIX 2: SUMMARY TABLE OF REVIEWS

| Authors | Year | Region | Population sample | Aim of study | Type of study | Main findings | Strengths & limitations |
|--|------|--------|-------------------|--|----------------------|--|----------------------------|
| Bacopoulou F., Greydanus, D.E., Chrousos G.P. | | Greece | • | To address reproductive and contraceptive issues in adolescent girls with chronic medical conditions in order to assist health-care providers when they counsel teenagers about contraceptive methods (any use of contraceptives) | Literature review | Safe and effective forms of contraception are available for almost every adolescent with a chronic condition; When selecting a method, the nature of the medical illness and the expressed desires of the teenager must be taken into account. Contraceptive choice must be individualised. The review describes evidence and highlights new recommendations for the use of almost all contraceptive methods in adolescents with a variety of chronic conditions; including adolescents with disabilities in order to reinforce the attention given to their sexual and reproductive needs. Adolescents with physical or developmental disabilities experience menstrual irregularity more often than their healthy peers for reasons, among others, thyroid diseases, and high prolactin levels or polycystic ovary syndrome induced by medication. Though intellectually disabled teenagers usually have delayed psychosexual development, they can still have sexual desire so pregnancy prevention must be considered. Suggested contraceptives, and contraindications e.g. In institutionalised patients the COC (low- | • |
| | | | | | | dose combined oral contraceptives), patch or vaginal ring could be used, but not all types of COCs are suitable for immobile teenagers. In outpatient | |

| | | | | | | psychiatric patients, compliance is an important issue and the progestin-only injectable or implants would be appropriate choices, though initial side effects may not be tolerated. For the adolescent with developmental delay, hygiene is an important issue and amenorrhoea (absence of a menstrual period) is desirable. | |
|--|------|----|--------------------------------------|--|----------------------|---|---|
| Banks LM, Zuurmond M, Ferrand R, Kuper H. | 2015 | UK | HIV/AIDS and disability in Africa | To systematically review evidence on the prevalence and risk of disabilities among children and adults living with HIV in sub- Saharan Africa. | Literature review | They indicate that HIV is strongly linked to disability, and HIV-related disability is common in this region. Evidence from this review indicates an overwhelming need to address HIV-related disability, from both a research and policy perspective. Because of its many challenges, prevention and management of HIV-related disability, requires inputs and coordination from both rehabilitation and HIV care providers. Currently, it is unclear to what extent HIV-related disability is included in the strategies of those working in the fields of HIV or disability/rehabilitation in the region. Further epidemiological and operational research is needed to better guide policy decisions. More studies on HIV- related disabilities would be useful, and the use of more comprehensive measures could elucidate the multi- systemic nature of HIV-related disability. Research is also needed to gain a better understanding of the social and biological impact of HIV- related disability over the life course and of the situation of children living | High quality review methods. Limitations: The majority of included studies were not population- based and used non-probability sampling. The results they present are not necessarily representative of all PLHIV. Many of the studies were clinic based, which affect the generalisability of the results. Median prevalence for each category or subcategory of disability should be interpreted with caution, given the wide range of different definitions, severities and methods of assessing a specific type of dis- ability between studies. |

| | | | | | | with HIV. There is an urgent need to scale up early access to ART among children and more research is needed to determine the best treatment strategies for preventing and mitigating disabilities. | Furthermore, outcomes are not disaggregated by factors. Observed associations in disability could be due to reverse causality. |
|----------|------|----|--|---|--|---|--|
| Banks, N | 2014 | UK | adolescents with and without an intellectual disability | To consider the evidence of gender differences in sexually harmful behaviour between adolescents with and without an intellectual disability based on social understandings of what is seen as culturally normal and what is seen as abusive behaviour. | Not systematized literature review | Adolescents with intellectual disabilities are likely to be at greater risk for developing interpersonal social difficulties and with initiating and inhibiting sexual behaviour because of underlying deficits in social interaction. Due to this lack of necessary social skills that enable young people to initiate and maintain fulfilling, and appropriate friendships, they seek instead the company of individuals with whom they feel more comfortable, including younger, and consequently, vulnerable children. This does not mean that adolescents with intellectual difficulties are potential sexual offenders, nor that a history of sexual abuse equates with a likelihood of sexual offending. There is a high prevalence of adolescents presenting with sexually harmful behaviours, and particular issues for understanding and supporting this area arise within the context of gender differences in offending and the additional difficulties affecting young people with intellectual disabilities. Educational and child psychologists have the potential to play an important role in this area in terms of both individual and multi-agency working. | Limitations: Did not mention methods. |

| Barger E., Wacker J., Macy R., Parish S. | 2009 | USA | women with intellectual disabilities | To summarize the findings of general sexual assault prevention research and discuss its implications for women with intellectual disabilities and to evaluate interventions for women with ID published in both the peer-reviewed and non-peer- reviewed literature and assess these programs for their efficacy and evidence-based results. | Literature review | First, women with intellectual disabilities are at increased risk for sexual violence victimization (Sobsey & Doe, 1991; Tyiska, 1998). Second, few sexual assault and developmental disabilities service agencies or researchers have been able to devote the resources needed to study and reduce the incidence of sexual violence against women with disabilities. Third, although service providers and researchers have offered important preliminary contributions, much work remains before an evidence-based sexual assault prevention program exists for women with intellectual and developmental disabilities. What is needed: to incorporate evidence Into Prevention Practice; sexual assault prevention programs for women with intellectual disabilities should have a comprehensive approach and should draw from what is known about effective prevention programs in general. | High quality review methods. Limitations: Each study was discussed, but not the overall limitation of the review |
|---|------|-----|---|--|----------------------|---|---|
| Berry, J.G., Bloom, S., Foley, S., Palfrey, J.S. | 2010 | USA | children with chronic health conditions | To describe health inequities experienced by children with chronic health conditions. | Literature review | Chronic health conditions, treatment, and outcomes are not evenly distributed among US children; in general, children of racial or ethnic minorities have greater health burden and experience poorer outcomes than white children. The results of this review indicate that we have a long way to go to ensure that all children, regardless of race or ethnicity, have comparable health burdens and receive the best health and developmental services available. | Some weaknesses to the review, e.g. no mention of limitations |

| Black K. | 2005 | UK | young people with special needs | To explore (inform and suggest) the need to overcome reluctance to address sexuality issues of young people with special needs in the context of evidence, policy and service provision and to provide recommendations for improvement of provision. | Not systematized literature review | Does not address females specifically. Nursing models and frameworks should incorporate the issue of sexuality to ensure holistic approaches to care. Implementation of existing policy (inclusive rights to health) would improve provision of sexual health services and resources - including equal access to services, premises with wheelchair access, simplified materials, suitable means of conveying information to individuals with sensory deficits and the availability of leaflets with illustrations that adolescents with physical impairments can relate to. Structured sexuality education sessions should continue to be provided to adolescents with special needs and delivered at an appropriate level of complexity, with input from the multidisciplinary team when required. Parents need to be empowered to | Limitations: No methods are mentioned. Based on author's observations and community experiences but backed by evidence in literature. |
|------------|------|--------|------------------------------------|--|--|---|--|
| | | | | | | children and to promote positive attitudes towards disability and | |
| | | | | | | sexuality in society. | |
| Conod L., | 2008 | Franca | Intellectual | The aim of the present | Not | Different authors have proposed that | Limitations: Methods |
| Servais L. | | | disabilities | paper is to identify the | systematized | the passive, obedient and affectionate | not mentioned. |
| | 1 | | | specific needs of | literature review | behaviour presented by many subjects | |
| | 1 | | | intellectually disabled | | may constitute a risk factor to sexual | |
| | 1 | | | patients towards | | abuse. About ID in general: The | |
| | | | | sexuality and the | | expectations of persons with | |
| | 1 | | | medical and educative | | intellectual disabilities towards sexuality | |
| | | | | support he/she needs | | vary considerably according to their | |
| | | | | according to his/her | | level of disability. Studies have found | |
| | 1 | | | disability and co- | | that the proportion of sexual activity in | |
| | 1 | | | morbidity and review | | women with mild disability living in the | |
| | | | | research conducted in | | community was similar to that of the | |
| | | | | this area. | | general population after adjustment for | |

| age and race. One study found that 18 and 42% of study subjects reported that they were currently or previously sexually active, respectively. However, prevalence seems to vary in institutionalised individuals. It seems that prevalence and expectations are dependent on opportunity as well. In one study, 82% of mildly disabled women living in a coeducational facility previously experienced sexual intercourse, whereas only 4% of those living in a non-coeducational facility did so. In another, 46% of mildly and moderately intellectually disabled people with no prior sexual experience communicated that they intended to become sexually active as soon as the opportunity presented. In general, there is a paucity of studies with large and representative samples assessing what persons with intellectual disabilities themselves expect from sexuality in terms of sexual intercourse as well as affective relationships, | I |
|--|---|
| they were currently or previously sexually active, respectively. However, prevalence seems to vary in institutionalised individuals. It seems that prevalence and expectations are dependent on opportunity as well. In one study, 82% of mildly disabled women living in a coeducational facility previously experienced sexual intercourse, whereas only 4% of those living in a non-coeducational facility did so. In another, 46% of mildly and moderately intellectually disabled people with no prior sexual experience communicated that they intended to become sexually active as soon as the opportunity presented. In general, there is a paucity of studies with large and representative samples assessing what persons with intellectual disabilities themselves expect from sexually in terms of sexual intercourse as well as affective relationships, | |
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| living in a non-coeducational facility did so. In another, 46% of mildly and moderately intellectually disabled people with no prior sexual experience communicated that they intended to become sexually active as soon as the opportunity presented. In general, there is a paucity of studies with large and representative samples assessing what persons with intellectual disabilities themselves expect from sexuality in terms of sexual intercourse as well as affective relationships, | |
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| Image: state of the state of | |
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| become sexually active as soon as the opportunity presented. In general, there is a paucity of studies with large and representative samples assessing what persons with intellectual disabilities themselves expect from sexuality in terms of sexual intercourse as well as affective relationships, | |
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| and representative samples assessing what persons with intellectual disabilities themselves expect from sexuality in terms of sexual intercourse as well as affective relationships, | |
| what persons with intellectual disabilities themselves expect from sexuality in terms of sexual intercourse as well as affective relationships, | |
| what persons with intellectual disabilities themselves expect from sexuality in terms of sexual intercourse as well as affective relationships, | |
| sexuality in terms of sexual intercourse as well as affective relationships, | |
| as well as affective relationships, | |
| | |
| | |
| marriage, and child raising. To support | |
| persons with ID with their sexuality | |
| expectations requires an evaluation of | |
| these expectations and of the specific | |
| needs in the areas of contraception, | |
| hygiene management, sex education | |
| and STI and abuse prevention. | |

| Dawn R. | 2014 | India | Women with | To address the problem | | There is unfortunately a lack of | Limitations: Methods |
|---------|------|-------|--------------|-------------------------|----------------|---|----------------------|
| | | | disabilities | of sexual assault of | various books, | prevalence data of violence against | not mentioned |
| | | | | women with disabilities | articles and | women with disabilities in India, though | |
| | | | | in the Indian context, | government | they are often reported in the media. In | |
| | | | | highlighting on some of | policies and | one study, nearly 2% physically disabled | |
| | | | | the loopholes in the | other related | and 22% mentally challenged women | |
| | | | | Indian legal system | documents | reported of being forced into sex or | |
| | | | | | | raped by family members. A | |
| | | | | | | considerable proportion of women did | |
| | | | | | | not file any report. In another study, | |
| | | | | | | 25% of women with mental disabilities | |
| | | | | | | and 13% of women with locomotor, | |
| | | | | | | visual and hearing disabilities reporting | |
| | | | | | | having been raped. In majority of the | |
| | | | | | | cases, the perpetrators were family | |
| | | | | | | members. Reasons for not reporting of | |
| | | | | | | abuse in general include the following: | |
| | | | | | | failure from those responsible for | |
| | | | | | | providing care, not being believed, need | |
| | | | | | | to take legal action, fear of reprisal or | |
| | | | | | | removal of privileges, not recognising | |
| | | | | | | abuse. In addition, criminal law in India | |
| | | | | | | does not adequately address the | |
| | | | | | | problem of sexual assault of women | |
| | | | | | | with disabilities, stemming from laws | |
| | | | | | | not reflecting the rights of women with | |
| | | | | | | disabilities. In addition is the problem | |
| | | | | | | with barriers at societal level, in | |
| | | | | | | understanding sexual violence based on | |
| | | | | | | sexual myths, lack of knowledge to | |
| | | | | | | recognise when sexual assault has | |
| | | | | | | occurred, a dependency relationship | |
| | | | | | | between victim and perpetrator, and | |
| | | | | | | the inability to communicate when an | |
| | | | | | | assault has occurred. Women with | |
| | | | | | | disabilities need to be provided with | |
| | | | | | | knowledge and a supportive | |
| | | | | | | environment, and the criminal justice | |
| | | | | | | system and social services need to | |

| | | | | | | respond. Policies need to ensure greater accessibility to complaint and the legal system needs to be strengthen to bring perpetrators to justice. | |
|---|------|--------|---|---|----------------------|---|--|
| DeForge D., Blackmer J., Garritty C., Yazdi F., Cronin V., Barrowman N., Fang M., Mamaladze V., Zhang L., Sampson M., Moher D. | 2005 | Canada | Persons with spinal cord injuries (SCI) and their partners | To study fertility of persons with spinal cord injuries (SCI) and their partners. | Systematic review | No studies investigated fertility in SCI females. Women addressed here: Articles stated that there is initial acute delay in the return of ovulation cycles in females following SCI (spinal cord injury), but there is no impact on female fertility by the injury. However, this is not supported by studies comparing women with and without SCI | Good quality review methods. However, article limitations were not discussed. |
| Deforge D, Blackmer J, Moher D, Garritty C, Cronin V, Yazdi F, Barrowman N, Mamaladze V, Zhang L, Sampson M. | 2004 | Canada | Persons with spinal cord injuries (SCI) | To study issues related to fertility, pregnancy rates, and live births in persons with SCI, and issues related to male impotence post-SCI. | Systematic review | No studies were found that investigated fertility in females after SCI. Of the 122 included studies, 78% of the studies reported 100% male participation, with only 6% reporting all female participation. Eight reports examined the phenomena of sexual arousal in response to physical and cognitive stimulation in women. These papers describe the separate roles of physical reflex and cognitive pathways in the sexual response in SCI females, but did not test treatment methods for dysfunction. There is a paucity of literature regarding fertility and pregnancy in SCI females. | Good quality review methods. No limitations discussed |

| Di Giulio G. 20 | 003 | Canada | people with disabilities | To examine key issues related to sexuality within the disabled population. | Not systematized literature review | Disability is simply one of many variables that may determine enjoyable sexual response for a particular individual. Persons acquiring a disability at birth or at an early age face different set of challenges than those acquiring disabilities later in life. Common issues regardless of disability and onset are systemic barriers to sexual health and include lack of privacy, reduced access to sexual health information and health care, and decreased access to sexual partners. Three important barriers include increased vulnerability to HIV/ ATDS, increased vulnerability to sexual exploitation and abuse, and a consistent lack of sexuality education for disabled youth. Broad societal changes will be necessary to remove systemic barriers to sexual health and parents, educators, caregivers and health professionals will | Limitations: Methods not mentioned |
|-----------------|-----|--------|-----------------------------|---|--|---|---------------------------------------|
| | | | | | | play key roles in advocating for the sexual rights of the disabled. The same basic criteria used to assess sexuality education for non-disabled youth are equally applicable to disabled children. So physically disabled students can participate in sexual education classes alongside their non-disabled | |
| | | | | | | classmates. Sexual exploitation and abuse also needs to be addressed for all persons with disabilities. They need to learn skills for personal safety. Effective sex therapy for disabled individuals and couples are guided by the same principles as sex therapy for non- disabled. Finally, sex therapists working with clients with disabilities should avoid over emphasizing sexual function | |

| | | | | | | and focus on intimacy and expanding clients' sexual repertoire, and build sexual self-esteem and not automatically assume that an individual's sexual difficulty is related to disability. | |
|----------------------------|------|-------|---|---|--|---|---|
| Doughty A.H., Kane L.M. | 2010 | USA | People with intellectual disabilities | To address the paucity of research on teaching sexual abuse protection skills to people with intellectual disabilities, by continuing where previous reviews left off and by including studies related to protection skills more generally in people with intellectual disabilities. | Literature review | Little empirical progress has been made. Only one study extended the scope to include physical and verbal abuse. Work needs to be extended to male participants, younger participants and participants with more severe intellectual and less effective verbal skills. Components that produced longer lasting skills must be isolated and include skills related to physical and verbal confrontations and other safety skills. | Some weaknesses to the review, e.g. no mention of limitations |
| Galdó Muñoz G. | 2007 | Spain | Children with disabilities | To provide a summary of knowledge on abuse of children with disabilities | Not systematized literature review (In spanish) | The article discusses that unfortunately we still label, stigmatize, devalue, depersonalise and reject children with disabilities, creating an atmosphere for abuse to occur. The article discusses the prevalence of abuse, how there are risk and protective factors within the child, its family and its social environment; the types of abuse including negligence, sexual, physical and psychological abuse; the indicators of abuse including physical, behavioural and parents behaviour; and prevention strategies targeting the community, the family and the children. | Methods were not mentioned. |

| Govindshenoy | 2007 | UK | Children with | To ascertain the | Systematic | Articles needed to be population based | Methods were well |
|--------------|------|----|--------------------|--------------------------|------------|---|----------------------------|
| ., М., | | | disabilities under | strength of the | review | studies reporting empirical data on the | explained, as well as |
| Spencer N. | | | 18 | association between | | association of abuse with disability. | inclusion/exclusion |
| | | | | childhood disability and | | Found weak evidence base for an | criteria and search |
| | | | | abuse and neglect. | | association of disability with abuse and | terms. High quality |
| | | | | _ | | neglect. There is a need for further high | review. Limitation |
| | | | | | | quality, population-based research in | discussed by authors: |
| | | | | | | this area, preferably a prospective birth | Wide variation in the |
| | | | | | | cohort of sufficient size to examine the | definitions of disability |
| | | | | | | association among different forms of | with the result that it is |
| | | | | | | disability. An alternative design would | impossible to pool |
| | | | | | | be population-based case-control | study findings and |
| | | | | | | studies involving samples of abused or | even difficult to make |
| | | | | | | disabled children and controls randomly | simple comparisons |
| | | | | | | selected from the same populations. | between studies. |
| | | | | | | | Definitions of child |
| | | | | | | | abuse and neglect |
| | | | | | | | differ in relation to the |
| | | | | | | | agent or agency |
| | | | | | | | identifying abuse. |
| | | | | | | | None of the studies |
| | | | | | | | adjusted for all |
| | | | | | | | potential confounding |
| | | | | | | | variables. Sample size |
| | | | | | | | was also a problem for |
| | | | | | | | two of the articles, due |
| | | | | | | | to difficulties in |
| | | | | | | | studying rare events. |
| Grieve A., | 2007 | UK | people with | To review the literature | Review of | Sex education packages (e.g. Adcock & | Limitations: No |
|--------------|------|----|------------------|--------------------------|--------------|---|-----------------|
| McLaren S., | | | moderate to | on issues surrounding | education | Stanley 1994; Craft et al. 1983; Dixon | methods are |
| Lindsay W.R. | | | severe learning | the sexuality of people | packages and | 1993; McCarthy & Thompson 1992) | mentioned |
| | | | disability (SLD) | with moderate to | assessments | generally require the people with | |
| | | | | severe learning | | learning disabilities to have an | |
| | | | | disability (SLD), and | | understanding of spoken and written | |
| | | | | evaluate available | | language, and can often require an | |
| | | | | assessment and | | element of abstract thinking, such as | |
| | | | | training methods. | | during role-play situations. Many | |
| | | | | | | packages have some pictorial support, | |
| | | | | | | but this is generally limited and is not | |
| | | | | | | always sufficient to depict or explain | |
| | | | | | | certain situations. In addition, although | |
| | | | | | | many of the sex education packages or | |
| | | | | | | programmes offer an informative and | |
| | | | | | | well-structured guide to providing | |
| | | | | | | training they do not generally provide | |
| | | | | | | information about the reliability or | |
| | | | | | | validity. Furthermore, some do not | |
| | | | | | | report the level of intellectual disability | |
| | | | | | | needed. A number of sexual knowledge | |
| | | | | | | questionnaires are not standardized, or | |
| | | | | | | do not have established psychometric | |
| | | | | | | properties. In addition, there is a lack of | |
| | | | | | | comparison tools which assesses the | |
| | | | | | | sexual knowledge of people with LD | |
| | | | | | | compared to people without LD. | |

| | Groce N.E., Rohleder P., Eide A.H., MacLachlan M., Mall S., Swartz L. | 2013 | UK | people with disabilities | To summarise what is currently known about the intersection between HIV and AIDS and disability, paying | Critical review | There is growing body of work, but gaps remain. Studies reviewed investigated levels of knowledge of AIDS, occurrence of unsafe sex and other risk behaviours, as well as access to HIV-related health care among people with disabilities. The majority of existing studies have concentrated on people with mental health problems, learning/intellectual disability or those who are deaf or hearing impaired. Far less is known about the broad range of risk of HIV among people with physical disabilities, those who are blind or have vision impairments, albinism or who are multiply disabled. More data are needed not only on prevalence of unsafe sex, but also about the interplay between disability and the various factors that facilitate sexual risk, such as poverty, substance abuse, and gender inequality. We also need to know more about the interaction between disability, gender, stigma, social isolation and risk behaviours. There are also large regions of the world with little or no evidence. Good statistical data are also needed on prevalence and behaviours. The literature suggests that there are various attitudinal and structural barriers to care, treatment and support for people with disabilities who are living with HIV or diagnosed with AIDS. Much more research and attention is needed on this. | Clear in what it is trying to accomplish. Quality review. Limitation as mentioned by author: Lack of representation of different types of disabilities, and the wide variation in prevalence rates, make the prevalence findings difficult to interpret. |
|--|--|------|----|-----------------------------|---|-----------------|--|---|
|--|--|------|----|-----------------------------|---|-----------------|--|---|

| Groce NE. | 2003 | USA | disabled people | Commentary on need to focus on HIV/AIDS in disabled people | Not review or study, but a commentary | There is a real need to understand the issue of HIV/AIDS in disabled people in global terms and to design and implement programmes and policy in a more coherent and comprehensive manner. The roughly 600 million individuals who live with a disability are among the poorest, least educated, and most marginalised of all the world's peoples. They are at serious risk of HIV/AIDS and attention needs to be focused on them. | Commentary |
|--------------------------------------|------|--------------|-----------------|--|---|---|---|
| Hanass- Hancock J., Satande L. | 2010 | South Africa | Deaf people | To provide an overview of the epidemiological drivers and trends in HIV infections among deaf people including historical, geographical and thematic factors, as well as the methodological strengths and weaknesses in the body of research on this topic to date | Systematic review | Most of the studies (14 of 17) focused on HIV/AIDS knowledge among the deaf population. Four studies explored the topic of HIV and AIDS from the perspective of reproductive health. Often the inaccessibility of health services and health education for deaf populations was pointed out, yet few studies explored this issue. Two studies focused entirely on comparing HIV- prevalence data among the deaf population with the national data in that particular country or district. Six studies worked with a control group, two of these used random sampling. Seven studies used a qualitative design, one focussing on the experience of being deaf and homosexual. Studies showed that deaf people are indeed sexually active. The review has found support for the common hypotheses that deaf people; a) might be more vulnerable to HIV infection, b) have less HIV/ AIDS knowledge, and c) have less | Well explained description of the studies. Weaknesses in literature, like quality, was discussed, but not limitation of review itself |

| | | | | | | access to HIV prevention and intervention programmes. Although some of the studies specifically mentioned sexual abuse, very little research has been done on sexuality and sexual abuse in relation to HIV among the disabled. | |
|---|------|-----|-------------|---|--|---|---|
| Hartman L.B., Monasterio E., Hwang L.Y. | 2012 | USA | adolescents | To review current contraceptive methods available to adolescents and to provide information, guidance, and encouragement to paediatric clinicians to enable them to engage in informed up-to-date interactions with their sexually active adolescent patients | Not systematized literature review | The article focuses on female contraceptives. Part dealing with disabled girls: Important for clinicians to consider youth with chronic conditions with disabilities as being sexual beings and having the same desires, drives and patterns of sexual behaviour as other adolescents, and similar debut age. Differences include that girls with multiple disabilities are more likely to desire pregnancy at first intercourse, and more likely to experience forced sex. Apart from the need for contraception for pregnancy, they may request menstrual management because of physical challenges or behavioural issues related to menstruation. It is essential that the clinician clearly ascertain the desired outcome. Potential drug interactions are of particular concern with youth with chronic conditions. They are more likely to be on long-term prescribed medications, and before engaging in contraceptive counselling, a detailed medication history is essential. For those youth with verbal or cognitive impairments, obtaining a complete medication history may require parental participation. Clinicians who provide services for adolescents have a | Limitations: No methods are mentioned |

| Jackson A.B., Mott P.K. | 2007 | USA | women with spina bifida | To examine gynaecologic and reproductive concerns of women with spina bifida | Not systematized literature review | responsibility to develop their skills and knowledge base so that they can be a source of counselling and support. However, studies of adult primary care providers find that many do not provide adequate counselling and contraceptive services in these situations, blaming lack of knowledge or time. The paediatric clinician, with the support of up-to-date resources, can manage most problems related to contraceptive method choice in young women with chronic conditions. A team approach is advisable. It is also important for clinicians to respect the confidentiality concerns of the youth. There is limited evidence on the reproductive systems of women with spina bifida and it is therefore difficult to address their gynaecological concerns. This means that in many cases clinicians have to rely on extrapolations of studies of women with similar disabilities concerning, e.g. female sexual response, and safest methods of birth control. What is known: Menarche (first menstrual cycle) occurs earlier in girls with spina bifida; due to their physical conditions, gynaecological exams may be very difficult; and they have an increased risk of developing latex allergies believed to be a result of the many surgical interventions, which they undergo. Due to a large series of surveys and case studies, more is known about obstetric | Limitations: No methods are mentioned |
|----------------------------|------|-----|----------------------------|--|--|---|---|
| | | | | | | studies, more is known about obstetric care and pregnancy. The physiological process of pregnancy and the effects of the growing fetus may exacerbate spina | |

| | | | | | | bifida sequelae. However, in studies, mostly healthy babies were delivered, with some being born with congenital malformations, though none with spina bifida. There is also an uncertainty of how much folic acid pregnant women with spina bifida should be taking. No studies have been published that explore the effects of menopause transition in women with spina bifida. Finally, it is difficult for women with spina bifida to maintain reproductive health due to lack of screening. | |
|--------|------|--------|---|--|--|---|---|
| Job J. | 2004 | Canada | individuals who are deaf or hard of hearing | To examine the dissemination of information on sexuality to people who are deaf or hard of hearing. | Not systematized literature review | Of the 3 most recent research described by this article, one confirmed the great lack of knowledge among deaf individuals in college, where the majority (80%) were sexually active yet only one third used condoms. The second suggested the possible factors for the gaps which persist between hearing and deaf students regarding sexual knowledge, and the third also uncovered a knowledge gap and reported on the persistence of misperceptions which exist in this population, including being able to get AIDS from giving blood, and that heterosexuals or married people cannot get AIDS. This lack of knowledge is then discussed in terms of the role the following factors play in the transfer of knowledge to deaf individuals: Insufficient opportunities to acquire information, parental reluctance to provide sexuality education, inadequate school-based instruction, and misinformation from peers. Then seven | Limitations: No methods are mentioned |

| | | | | | | "mythconceptions" based on myths from literature from individuals with intellectual disabilities are discussed: deaf individuals are asexual, they need to be protected within asexual environments, should not be provided with sexual education to discourage inappropriate behaviour, they should be sterilized, they are sexually different, they are oversexed, promiscuous and dangerous, and they cannot benefit from sexual counselling. | |
|-------------------------|------|-----|------------------|---|--|--|--|
| Joffe, H., Hayes, F. | 2008 | USA | adolescent girls | To discuss the prevalence of epilepsy, bipolar disorder, and migraines in adolescent girls, their association with menstrual dysfunction and the effect of antiepileptic drugs (AEDs) and antipsychotics on these common disorders. | Not systematized literature review | Valproate is a highly effective antiepileptic drug used widely to treat epilepsy, bipolar disorder, and migraines. Despite the potential reproductive health risks associated with use of specific antiepileptic drugs and selective antipsychotics, these agents are vital treatments for adolescents with severe illnesses. Alternative treatments for epilepsy, bipolar disorder, and migraines may be important considerations, but have their own side effects and risks that should be weighed in the selection of specific medication treatments. Use of these agents should be considered and weighed against the risk of not treating these serious neurologic and psychiatric disorders. | Limitations: No methods are mentioned. |

| Jones L., Bellis M.A., Wood S., Hughes K., McCoy E., Eckley L., Bates G., Mikton C., Shakespeare T. | 2012 | UK | children with disabilities | To synthesise evidence for the prevalence and risk of violence against children with disabilities | systematic review and meta-analysis | Children with disabilities are more likely to be victims of violence than are their peers who are not disabled. However, the continued scarcity of robust evidence, due to a lack of well-designed research studies, poor standards of measurement of disability and violence, and insufficient assessment of whether violence precedes the development of disability, leaves gaps in knowledge that need to be addressed. | High quality review. Limitations mentioned by authors: 1) the potential for reverse causation, 2) significant heterogeneity between all of the pooled estimates due to differences in definition of disability. This resulted in lack of clarity of meta- analysis. 3) The prevalence within the population sample was investigated in only one study included in the systematic review. Pooled risk estimates might have overestimated the association between violence and disability. |
|--|------|---------|--|--|---|---|---|
| Katalinic S., Sendula-Jengic V., Sendula- Pavelic M., Zudenigo S. | | Croatia | individuals with intellectual disabilities | To examine issues concerning reproductive rights of individuals with intellectual disabilities, in light of legislation in Croatia | Not systematized literature review | Article is summarized in terms of four topics: Perceptions of sexuality of people with intellectual disabilities throughout history; Reproductive health care of women with intellectual disabilities; Sexuality in people with intellectual disabilities; Rights of people with intellectual disabilities in Croatia. The system must be built on foundations that satisfy the needs of its users, but also of persons engaged in work with them. Sex education should contain information regarding biological, socio-cultural and spiritual dimensions of sexuality, including | Limitations: No methods are mentioned |

| | | | | | | cognitive, affective and behavioural domains. | |
|--------------------------|------|--------|--|--|--|---|---|
| Mahoney A., Poling A. | 2011 | USA | people with severe developmental disabilities | To summarize the relevant literature regarding sexual abuse in people with severe developmental disabilities and offer suggestions for future research | Not systematized literature review | Researchers need to prioritize developing effective sexual abuse prevention strategies tailored for people with severe cognitive and other disabilities, e.g. by ascertaining whether interventions shown to be useful in teaching people with mild to moderate developmental disabilities to avoid sexual abuse can be adapted for use with people with more severe disabilities. Staff-training programs that, for example, teach caregivers how to detect and report signs and symptoms of sexual abuse and to minimize the likelihood of abuse needs to be evaluated. Organizations should also consider incorporating an abuse- prevention model into their management system. | Limitations: No methods are mentioned |
| Martinello E. | 2014 | Canada | individuals with intellectual disabilities | To examine risk factors across development domains for sexual abuse among individuals with ID and strategies to support early intervention to increase competency in these areas | Not systematized literature review | Individuals with special needs are at an increased risk for sexual assault during childhood as compared to their typically developing peers. Developmental delays across domains may influence the likelihood of sexual abuse. For example, motor delays may limit un/dressing and other self-care tasks, social delays may inhibit appropriate peer relationships, cognitive delays may prevent a child from discerning abuse from care, language delays may prohibit a child from reporting abuse or rejecting an inappropriate advance, and emotional delays may affect a child's | Limitations: No methods are mentioned |

| | | | | | | self-esteem with intellectual disabilities. Care providers are frequently cited as the most likely perpetrator of sexual abuse against children with intellectual disabilities, and are likely to be known to the child prior to the abuse occurring. A strong foundation for healthy sexuality across the lifespan begins in the early years. Addressing each potential risk factor by providing both explicit sexuality education and ongoing opportunities for skill- acquisition in each area, can help to keep children with IDs safe, and allow them the chance to experience healthy, consensual sexuality. | |
|---------------|------|--------|--|---|--|--|--------------------------------------|
| Martinello, E | 2015 | Canada | individuals with intellectual disabilities | To examine the duality of simultaneously being victim and perpetrator, the potential need for education/support and direct consequences, and the balancing act of supporting a potential perpetrator whilst protecting potential victims. | Not systematized literature review | Individuals with IDs are at increased risk for experiencing sexual abuse as compared to their typically developing peers, often perpetrated by other individuals with IDs. Individuals with IDs may be at higher risk for perpetrating abuse because of their own experiences with sexual abuse laying a foundation for how they perceive sexuality. Additionally, knowledge gaps in prerequisite skills may limit their ability to engage in appropriate expressions of sexuality. It is recommended that individuals with IDs engage in ongoing comprehensive early sexuality education programs in order to promote capacity building, and address factors that may place them at increased risk for perpetrating or receiving abuse. It is important to view individuals within their own contexts, understanding their own strengths and | Limitations: No methods mentioned |

| | | | | | | needs. Providing sexuality education to all individuals with IDs can help to address both risk reduction (i.e., their risk of being victimized) and prevention (i.e., their risk of perpetrating abuse), and promote opportunities for expressing appropriate relationships and expressions of sexuality. | |
|-------------------|------|-----|----------------------------------|--|--|--|--------------------------------------|
| McEachern A.G. | 2012 | USA | individuals with disabilities | To review several studies conducted on sexual abuse of individuals with disabilities with a focus on clinical prevention strategies. | Not systematized literature review | Professionals must be trained on warning signs of sexual abuse as well as mandated reporting practices. Prevention training programs for children and adults with disabilities must be regularly implemented by support services. Prevention strategies include advocacy and awareness among providers, early conversations with parents regarding sexual development, individualized sexual education, training on detection of sexual abuse, encouraging communication between parent and child, communication cue between individual and caregiver, home visits by clinicians, support group for parents and caregivers, and team approach. Sexuality education must be conducted early and regularly. In addition, prevalence and incidence of abuse is currently difficult to determine due to studies not using comparable variables, or distinguishing between disability types. Only limited research is available on the efficacy of clinical prevention and treatment programs. | Limitations: No methods mentioned |

| McGuire B.E., Bayley A.A. | 2011 | Ireland | people with intellectual disability | To summarize the current status of our knowledge and clinical practice in the complex and challenging area of relationships and sexuality for people with an intellectual disability | Not systematized literature review | Recent surveys of caregivers and service providers show a greater awareness of the fact that sexuality is a central part of personal identity, yet generally, restrictive or prohibitive attitudes prevail at both individual and organizational levels. These attitudes appear to reflect a fear of possible legal sanction as well as ethical and moral conflicts. The views and experiences of people with an intellectual disability generally confirm this impression that, whereas some small changes have taken place, the prevailing experience is of restriction. There is now an abundance of sexuality and relationship educational programmes available; however, they require more rigorous and systematic evaluation both in terms of their effectiveness for enhancing knowledge and for examining the impact of that education on behaviour and capacity to make sexuality-related decisions. | Limitations: No methods mentioned |
|--|------|-------------|---|--|--|--|---|
| McLay L., Carnett A., Tyler-Merrick G., van der Meer L. | 2015 | New Zealand | children and adolescents with developmental disabilities | To analyse studies that evaluated interventions for inappropriate sexual behaviour of children and adolescents with developmental disabilities. | systematic review | All of the 12 studies reported decreases in the target behaviour as the result of intervention. The most common intervention involved the use of multi- component behavioural strategies. The use of a multi-component behavioural intervention can aide in the reduction or elimination of ISB, but it is difficult to isolate which components of the intervention were effective. However, it appears that the use of differential reinforcement procedures and the teaching of appropriate replacement skills are important components of intervention for ISB. Though ethically | Quality review. Limitations reported by authors: The small number of participants that are included in each study threatens the external validity of the findings and makes it difficult to generalize the study outcomes across age, gender, disability, IQ, and sexual behaviours. Direct recording of the ISB were often not |

| | | | | | | controversial, in some cases, it is possible that overcorrection, may be an effective component of the treatment protocol as well as use of medication. Given this possibility, a complete functional assessment of the ISB might be warranted in the development of an intervention plan. It is very important to consider the home and community impact of learning. In spite of an ideological shift in the way in which the sexual behaviour of people with developmental disabilities is viewed, the approach to treatment of ISB between 1977 and 2009 remains relatively unchanged. Finally, very few studies included female participants. | conducted, or specific changes in ISB data were not presented, and there is bias associated with use of self-reporting. |
|---|------|-----|---------------|--|-----------------------------------|---|--|
| Moorthy L.N., | 2010 | USA | children with | To review the burden | Not | Juvenile arthritis imposes a significant | Limitations: Methods |
| Peterson M.G.E., Hassett A.L., Lehman T.J.A. | | | arthritis | of juvenile arthritis for the patient and society | systematized literature review | burden on different spheres of the patients', caregivers' and family's life. In addition, it imposes a societal burden of significant health care costs and utilization. Juvenile arthritis affects health related quality of life, physical function and visual outcome of children and impacts functioning in school and home. The extent of impact on the various aspects of the patients', families' and societal functioning is clear from the existing literature. Effective, well-designed and appropriately tailored interventions are required to minimize the burden on costs; enhance transitioning to adult care, improve school function and future vocation/occupation and overall the long-term outcome of patients. | were not mentioned |

| Murphy N., | 2005 | USA | children and | To discuss sexual | Not | This review provides an overview of | Limitations: Methods |
|------------|------|-----|------------------|-------------------------|-------------------|--|----------------------|
| Young P.C. | | | adolescents with | development of | systematized | physical changes of puberty, | were not mentioned |
| | | | disabilities | children and | literature review | gynaecological issues, developmental | |
| | | | | adolescents with | | processes, sexual activities, decision | |
| | | | | disabilities, described | | making about contraceptives, myths | |
| | | | | in the ICF framework | | and social barriers, sexual victimization, | |
| | | | | | | and educational rights. Research related | |
| | | | | | | to sexuality and disability has focused | |
| | | | | | | more on females than males. Overall, | |
| | | | | | | adolescents with disabilities seem to be | |
| | | | | | | participating in sexual relationships | |
| | | | | | | without adequate knowledge and skills | |
| | | | | | | to keep them healthy, safe, and | |
| | | | | | | satisfied. Sexuality education empowers | |
| | | | | | | children with disabilities to enjoy | |
| | | | | | | personal sexual fulfilment and to | |
| | | | | | | protect themselves from abuse, | |
| | | | | | | unplanned pregnancies, and sexually | |
| | | | | | | transmitted diseases. Health care | |
| | | | | | | providers must accept this challenge | |
| | | | | | | and advocate the rights of all children | |
| | | | | | | to grow into socially and sexually | |
| | | | | | | competent adults, including those with | |
| | | | | | | disabilities. They should advocate | |
| | | | | | | independence in children with | |
| | | | | | | disabilities by discussing many of these | |
| | | | | | | issues in private with the child, although | |
| | | | | | | informing the parents of the general | |
| | | | | | | topics of discussion may be appropriate. | |
| | | | | | | Individualized education plans should | |
| | | | | | | include the provision of sexuality | |
| | | | | | | education for children with disabilities. | |

| Murphy N.A., Elias E.R. | 2006 | USA | children and adolescents with disabilities | To discuss the issues of puberty, contraception, psychosexual development, sexual abuse, and sexuality education specific to children and adolescents with disabilities and their families. | report | Much of the same information in the previous article. Paediatricians, are encouraged to discuss issues of sexuality on a regular basis, ensure the privacy of each child and adolescent, promote self-care and social independence among persons with disabilities, advocate for appropriate sexuality education, and provide ongoing education for children and adolescents with developmental disabilities and their families. Paediatricians should incorporate guidance on sexuality education, socially appropriate behaviour, and sexual abuse prevention into the clinical supervision of all children, including children with disabilities. | Limitations: Methods were not mentioned |
|---|------|-----------|--|--|---|--|--|
| Nguyen T.T.A., Liamputtong P., Monfries M. | 2016 | Australia | people living with physical disabilities | To use the meta- synthesis methodology developed by Noblit and Hare, to review qualitative studies in the areas of reproductive and sexual health of people with physical disabilities in both developed and underdeveloped nations. | Review of qualitative studies using metasynthesis methodology | Internal and external factors influence the reproductive and sexual health of people with physical disabilities. Internal factors refer to factors derived from personal constructs such as knowledge, attitudes, and psychological factors. External factors that influence the reproductive and sexual health of people with physical disabilities include stigma, gender role, education/family, partners, health services, finances, and transportation. Implications for health and social care regarding people with disabilities are the following: 1) More knowledge about reproductive and sexual health maintenance is needed; 2) Policies to improve accessibility of health centres are needed; 3) Strategies to provide reliable information related to reproductive and sexual health are needed 4) Improving understanding of | Well documented review of qualitative studies using meta- synthesis methodology. |

| | | | | | | disabilities among providers is needed. Furthermore, more research in developing countries is needed. | |
|-------------|------|-----|--|---|--|---|---------------------------------------|
| Quint, E.H. | 2008 | USA | Teens with DD (developmental disabilities) | To review issues concerning menstruation and reproduction in teens with DD | Not systematized literature review | The review assessed the impact of the menstrual cycle on teenagers with DD, including hygiene issues, menstrual irregularities due to specific clinical circumstances, and treatment dilemmas associated with the use of hormonal medication. Medical care providers should work with patients, parents, and caregivers to find an acceptable course of action for the management of menstrual issues for teens with DD, taking care of their vulnerability. If the cycles are restricting regular activities and affecting the teen's life, treatment can be initiated and periodically evaluated and assessed. There is a paucity of data on treatment options specific for women with DD. | Limitations: Methods not mentioned |
| Rosen DB. | 2006 | USA | women and girls with disability | To explore issues concerning women and girls with disability who have experienced violence and exploitation. | Not systematized literature review | Owing to different methodologies of data collection, it is difficult to determine the exact number of women and girls with disabilities who suffer violence and exploitation, but literature suggests that it occurs at a 50% higher rate than in the rest of the population. The literature also points out some critical issues including professional insensitivity and lack of knowledge regarding rights and laws among women and girl with disabilities. Laws that protect them need to be reinforced, resources needs to be made available to this group, professionals | Limitations: Methods not mentioned |

| | | | | | | and other service workers need to be educated on how to protect this group, and data collection needs to be standardized in order find prevalence and incidence for policymaking. | |
|--|------|-------------|--|---|----------------------|--|--|
| Schaafsma D., Kok G., Stoffelen J.M.T., Curfs L.M.G. | 2015 | Netherlands | individuals with intellectual disabilities | To identify effective methods for teaching sex education to individuals with intellectual disabilities. | Systematic review | Studies revealed that generalization of learned skills to real-life situations was often not achieved. There are indications that the maintenance of knowledge and skills still needs extra attention. Although there is some evidence for methods that may improve knowledge, attitudes, and skills with regard to sex education aimed at individuals with intellectual disabilities, it is unclear under which conditions these methods work. There is a need for more detailed descriptions of program materials, the goals of the program, and the methods used and how these are affected by practical or political decisions. Programs need to formulate goals more specifically. Current program goals are too broad. A standardized taxonomy of methods would make it easier to replicate effective interventions. There is also a need to look at theoretical methods for improving measures of knowledge attitudes and skills in individuals with intellectual disabilities. Researchers should publish intervention manuals with detailed descriptions of methods. More skills to real-life situations should be considered. Assessing skills in situ is important, though some self-reporting might be more appropriate in some | analysed. Differences in participants' demographics were not taken into account in this study due to heterogeneity across |

| | | | | | | cases. It is important to consider type of research design for testing effectiveness of sex education programs or materials, e.g. multiple baseline designs, for smaller samples and pretest-posttest for larger samples. Follow-up measurements are also necessary. | |
|---|------|---------|--|---|-------------------------|--|--|
| Sebald A.M. | 2008 | USA | children with hearing loss | To provide an overview of information on child abuse and hearing loss, identifying evidence on prevalence, types of abuse, and thus research needs. | Overview of research | Research has only been able to establish that abuse does occur within the population of children who are deaf or hard of hearing, however little other information exists. Reasons relate to a lack of quantity and quality in research on this population; challenges in conducting research using sound methodological principles that consider the population's heterogeneity (e.g., mode of communication, language level, parental perspective on deafness, educational placement); and scarce intervention services with professionals trained in the unique needs of children with hearing loss. It is important to expand and build upon existing research base using more methodological approaches and to design a system that consistently and uniformly identifies children with disabilities who are abused. | Limitations: Methods not mentioned. |
| Seidel, A., Wienholz, S., Michel, M., Luppa, M., | 2014 | Germany | adolescents with physical disabilities | To answer how sexual knowledge is provided for adolescents with physical disabilities. | Systematic review | Subjects researched were between 11 and 25 years old. Nine papers were identified, only one was highly informative. The majority of | Described limitations of articles, but little on how it affected conclusions. |

| Riedel-Heller, S.G. | | | | | | adolescents with disabilities get sexual education in school. Transfer of information is confined to the prevention of pregnancy, sexually transmitted diseases and harassment. Interdisciplinary sexual education is key to self-determined and well informed sexual life for adolescents with and without disabilities. For people with disabilities there should be information available with respect to their physical limitation. Almost all studies of this review excluded adolescents with severe and multiple disabilities. | |
|------------------------------|------|----|---|--|-------------------------------|--|--|
| Sequeira, H., Hollins, S. | 2003 | UK | people with learning disabilities | To critically review research on the psychological reactions of people with learning disabilities to sexual abuse | Critical literature review | Several studies suggest that following sexual abuse, people with learning disabilities may experience a range of psychopathology similar to that experienced by adults and children in the general population. However, because of methodological limitations, these results are not conclusive. | Limitations: The findings can only be seen as indicative: No controlled studies; The criteria used to report sexual abuse are inadequately or inconsistently defined in the studies; Few of the studies reviewed have used standardised assessments or samples from non- clinically referred sources. |

| Servais L. | 2006 | Belgium | Persons with | To review scientific | Not | The limited existing data indicate that | Limitations: Methods |
|------------|------|---------|--------------|---------------------------|-------------------|---|----------------------|
| | | | intellectual | studies that have | systematized | people with ID demonstrate poor sexual | not mentioned |
| | | | disabilities | assessed the | literature review | health knowledge and attitudes but | |
| | | | | expectancies and | | express sexual health desires and | |
| | | | | support needs of | | needs. People with moderate or severe | |
| | | | | persons with | | ID are less sexually active than the | |
| | | | | intellectual disabilities | | general population but are highly | |
| | | | | in terms of sexual | | susceptible to sexual abuse. | |
| | | | | health. | | Surveillance data regarding incidence | |
| | | | | | | rates of STDs and unplanned | |
| | | | | | | pregnancies are either lacking, dated, or | |
| | | | | | | restricted to certain subgroups (e.g., | |
| | | | | | | institutionalized) that are not | |
| | | | | | | representative of the larger population. | |
| | | | | | | In addition, differences in disability | |
| | | | | | | services make it inappropriate to | |
| | | | | | | generalize data across countries. As a | |
| | | | | | | result, a great deal of research is | |
| | | | | | | needed to (1) provide a more | |
| | | | | | | comprehensive picture of sexual health | |
| | | | | | | in people with ID according to gender, | |
| | | | | | | severity level, and living environment | |
| | | | | | | and (2) develop effective evidence- | |
| | | | | | | based practices designed to facilitate | |
| | | | | | | individual autonomy and control over | |
| | | | | | | sexual health among these individuals. | |
| | | | | | | There are several specific areas in which | |
| | | | | | | additional research on sexual health | |
| | | | | | | and people with ID is needed including: | |
| | | | | | | people with ID living in communities, | |
| | | | | | | sexual health of men with ID, | |
| | | | | | | effectiveness of sex education | |
| | | | | | | programmes regarding sexual health | |
| | | | | | | practices and abuse prevention, | |
| | | | | | | experimental designs to ascertain | |
| | | | | | | effectiveness of sexual health | |
| | | | | | | interventions and treatments. An | |
| | | | | | | individualized, person-centred, | |
| | | | | | | multidisciplinary approach including | |

| | | | | | | individuals themselves should be used to provide comprehensive sexual health care to persons with ID. Health care professionals can best advocate for and support the sexual health needs of people with ID by assessing contraception, hygiene management, STDs, and abuse prevention expectancies from the individual, whenever possible, rather than from the caregiver's perspective. | |
|---|------|-----|--|---|----------------------|--|---|
| Sevlever M., Roth M.E., Gillis J.M. | 2013 | USA | individuals with autism spectrum disorders | To address the characteristics of autism spectrum disorders (ASD) population, and how they relate to both victimization and offending. | Literature review | The current literature indicates the core characteristics of ASD puts individuals at risk for both sexual abuse and offending. However little is known about what puts them at risk or how they respond to sexual abuse. Systematic research is needed aimed at determining the prevalence and risk factors of both sexual abuse and offending within the ASD population. Until this happens, development of treatments tailored for offending individuals or sexual abuse victims will not be possible and not likely to be funded. There is also very little research examining sexuality education for individuals with ASD. Some programmes use clinicians, however others suggest parent or teachers as better sexuality educators. There are several barriers involved in implementing sex education for individuals with ASD, including social and political barriers and myths surrounding their sexuality. In light of inclusive education, it is important to | Weak description of methods. Described some limitations with some of the evidence. |

| | | | | | | teach individuals with ASD appropriate social behaviours, appropriate sexual behaviours, safety skills, and to promote positive peer interaction. Education should be individualized, comprehensive, addressing gender identity and homosexuality, and focussed on self-determination and the entire lifespan. | |
|-----------------------------------|------|-----|----------------------------|--|--|--|---------------------------------------|
| Stockburger, S.J., Omar, H. | 2015 | USA | women with disabilities | To provide an overview of sexual health and reproductive care issues for women with disabilities | Not systematized literature review | It is important to remember that children, adolescents, and women with disabilities go through the same stages of sexuality development and puberty as those without disabilities. Women with disabilities are less likely to receive gynaecological exams, contraception, and evaluation of sexual dysfunction. Unfortunately, having a disability places women at risk for sexual exploitation and abuse as well as sexually transmitted infections. Therefore, reproductive health care for these women is imperative. A number of studies have shown that proper and comprehensive education for women with disabilities themselves, their schools, caregivers, and health care providers about reproductive issues is key to improving reproductive health care. Education is necessary to change attitudes, which in turn will determine the quality and support for women with disabilities have the same needs for sexual expression and reproductive care as women without disabilities. | Limitations: Methods not mentioned |

| Suris JC., Michaud PA., Viner R. | 2004 | Switzerland | adolescents with chronic conditions | To analyse the reciprocal effects of chronic conditions and adolescent development | Literature review not described in this version | Approximately one adolescent out of ten has a chronic condition that somehow limits his or her daily activities. There is substantial evidence that chronic conditions can affect adolescent development (biological, psychological, and social development) and that adolescent development can have an effect on the condition. Adolescence is a time of rapid changes and turmoil. Teenagers with chronic conditions have an additional burden. However, in comparing them to their healthy peers, there seem to be more commonalities than differences. They need the same guidance and prevention as any other adolescent. | This version does not include a methods section (shortened version of article) |
|--|------|-------------|---|--|--|--|---|
| Timms S., | 2002 | USA | adolescents with | To review literature on | Not | Adolescent with intellectual disabilities | Limitations: Methods |
| Goreczny A.J. | | | and without intellectual disabilities | lack of social skills of adolescents with intellectual disabilities and on adolescent sex offenders, including individuals with intellectual disabilities. | systematized literature review | appear to be at high risk for developing interpersonal problems due to lack of social skills. With the increase in sexual awareness and behaviour during adolescence, certain individuals may present problems in social and sexual behaviour. Adolescent sex offenders are a primarily male, heterogeneous population representing all ethnic, racial, and socioeconomic groups. Various offender characteristics, such as victim history, choice of victim and degree of necessary therapeutic control are differences, which begin to be studied. Adolescent sex offenders with intellectual disabilities, have distinct difficulties that need to be addressed, including the predisposition of locking into an inappropriate behavioural pattern, weakened processing and evaluating skills, and limited social | not mentioned |

| | | | | | | competency. Literature suggests that early identification and treatment may be the best solution towards prevention of the effects of reinforcement on adult offending behaviour. However, there is almost no empirical literature addressing treatment or assessment of adolescent sex offenders who have intellectual disabilities. Instead, clinicians have only general recommendations to consider when assessing for deviant sexual behaviour. Although these guidelines are helpful, they do not reflect the imperative need for refined and empirically validated assessment measures that address the multiple considerations required in assessing youth who sexually offend. Important areas for research include causes, risks and maintenance of inappropriate behaviours, social and individual risks, standardised assessment tools, and assessment of treatment outcomes. | |
|---------------------------------|------|--------|---|---|--|--|---------------------------------------|
| Tutar Güven Ş., Isler, A. | 2015 | Turkey | children with intellectual disabilities | To emphasize the importance of sexual education for children with intellectual disabilities and the role of nurses in sexual education. | Not systematized literature review | Because of misconceptions about the sexuality of individuals with intellectual disabilities, this group is not being provided with sexual education. However, it is known that those with intellectual disabilities are at greater risk of sexual abuse. When these individuals are not informed about sexuality, they have difficulty identifying their experiences and perceiving that exploitative behaviours are wrong. In addition to providing this information as a precautionary measure to prevent sexual abuse, remedial interventions are also needed. Also, in order to | Limitations: Methods not mentioned |

| | | | | | | protect these individuals from sexual abuse, nurses, who play a key role in protecting public health, should, in cooperation with other health professionals, enable them to receive sexual education in accordance with their developmental levels | |
|---------------------------|------|-----|--------------------------|---|------------------------|--|---------------------------------------|
| Vernon M., Miller K.R. | 2002 | USA | children who are deaf | To provide an overview of issues involved in sexual abuse in schools and in society, describe some characteristics of paedophiles and hebephiles, and suggest how to prevent sexual abuse in schools. | Summary of evidence | Historically, service organisations, including deaf schools, handled child sexual abusers by either keeping it a secret, reprimanding the offender, or moving the offender to another location or school. School administrators were either fearful or did not fully understand the nature of sexual abuse. Sexual abuse can enter schools through school staff, through child sexual experimentation or through child re- enactment of sexual abuse occurring at home. Therefore, it is important to have an ongoing comprehensive prevention programme in schools that addresses the problem at all age levels. Special attention should be given to screening all applicants for employment, including telephone calls to references. Finally, it is essential that childcare workers and parents be aware of the behavioural and physical symptoms of sexual abuse. | Limitations: Methods not mentioned |

| Visconti D., Noia G., Triarico S., Quattrocchi T., Pellegrino M., Carducci B., De Santis M., Caruso A. | 2012 | Italy | Young women with spina bifida (SB) | To provide an overview of sexual education, sex functioning and sexual activity among adolescents with spina bifida. Moreover, | Not systematized literature review | Despite their disabilities, many adolescents with SB are sexually active or demonstrate sexual desires. Urinary incontinence and orthopaedic impairments have a great impact on sexual relationships. Consequently, these patients need accurate counselling about the sexual problems associated with their disease. Female adolescents with SB desire better knowledge about fertility, birth control and heredity issues of SB. Although precocious puberty is a common problem among girls with SB, disorders of menstruation are not described. Women with SB are usually fertile. Those who desire to become pregnant should have accurate pre-conception counselling. Due to the increased risk of having a newborn with SB, they should have an early prenatal diagnosis and the intake of a higher dose of folic acid (4–5 mg daily) is recommended. Expert urological management is required for the specific treatment of several bladder and bowel issues, which are exacerbated by pregnancy. If secondary contraindications are absent, vaginal delivery is recommended, though it might aggravate their urinary incontinence. | Limitations: Methods not mentioned |
|---|------|-------|--|---|---|--|---------------------------------------|
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| Weckesser A., Denny E. | 2013 | | women living with epilepsy | To investigate the experiences of pregnancy in women living with epilepsy through a review and synthesis of existing literature. | Literature review | One qualitative study was identified that directly investigated women's' experiences of epilepsy during pregnancy. Many of the findings from the 16 remaining publications were found to be limited in generalisability due to small sample sizes and/or the poor quality of data. A theme found throughout the literature was the lack of appropriate, timely and quality information for women living with epilepsy when having children, and accessing healthcare services. This is not only due to failure in practitioner-patient communication, but also on lack of knowledge among neurologists. There is a need for improved preconception, pregnancy and postnatal supports and information for women living with this condition. | Limitations: Some weaknesses in explaining the review methods used. Limitations mentioned in review included: Cultural difference could not be explored due to restriction of literature published in English only. Much of the literature is limited in generalisability. Available experiential knowledge available could not be used because review was limited to peer- reviewed sources only. Six included qualitative studies did not distinguish which experiences belonged to the group of interest. |
|------------------------------|------|-------------|-------------------------------|--|----------------------|---|---|
| Wiegerink | 2006 | Netherlands | adolescents and | To investigate | Literature | There is some evidence that | Limitations: Since |
| DJ, | | | young adults of | possible barriers to | review | personal factors such as psycho- | literature originated |
| Roebroeck | | | normal | successful social and | | logical adaptation, self-efficacy and | mainly from Canada, |
| ME, | | | intelligence with | sexual relationships | | sexual self- esteem are important | the USA, Western |
| Donkervoort | | | cerebral palsy | in adolescents and | | for developing social and sexual | Europe and |
| Μ, | | | | young adults of | | relationships. But environmental | Australia, it may not |
| | | | | | | factors such as family, peers, | be applicable outside |

| Stam HJ, Cohen- Kettenis PT. | | | | normal intelligence with cerebral palsy. | | attitudes of others and transportation and social and dating activities influence the personal factors and in this way have an indirect influence on social and sexual relationships. More insight is needed into how these factors may interrelate and their combined effect on the social and sexual relationships of adolescents and young adults with cerebral palsy | of these societies. In most of the included papers, social and sexual relationships was only one of the various issues included in the studies. Regarding the factors associated with social and sexual relationships, studies included either only used descriptive statistics, qualitative methods, or small samples. |
|--|------|-------------|------------------|--|---------------------|---|---|
| Wissink I.B., van Vugt E., Moonen X., Stams G.J.J.M., Hendriks J. | 2015 | Netherlands | children with ID | To review the scientific literature on the extent and nature of sexual abuse involving children with ID and on the reactions following the abuse. | Narrative review | The results confirm that children with ID are very vulnerable and at a higher than average risk for sexual abuse. Actually, of all children with disabilities, children with ID are among the highest risk groups for sexual abuse, with those with milder levels of ID being most at risk. Studies did not explicitly address what makes children with ID vulnerable. Studies have suggested the several reasons: lack of knowledge among children about what is acceptable sexual behaviour, emotional and social immaturity compared to chronic age, and dependence on caregivers making them less combative to authority | Quality review. Methods were clear. Limitations: It is difficult to draw general conclusions regarding sexual abuse of children with intellectual disability (ID), due to differences in methods and definitions of ID and sexual abuse used. |

| figures and more trusting. Authors agreed that educating and training |
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| could reduce this vulnerability. |
| Preventive measures include |
| training in protective skills, |
| establishing rules about sexual |
| behaviour of children and |
| professionals, and improving the |
| understanding of children's rights in |
| relation to sexual abuse. Training |
| required working with concrete and |
| applied situations, working in small |
| steps and repeating. Greater |
| consensus in terms of the |
| definitions, types, and measures of |
| disability and abuse is needed. |
| Considering context is also |
| important. More information is also |
| needed about sexual development |
| and sexual behaviour of children |
| with ID. Most studies were |
| quantitative in nature. Qualitative |
| research could provide more |
| information about the situation of |
| the abuse itself, about what has |
| happened, how the abuse started, |
| the development from there, how |
| children experience being pressured |
| or seduced. |