The sexual health knowledge of people with intellectual disabilities: A review.

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Abstract

There is a growing recognition that people with disabilities have the same sexual needs and rights as people without disabilities. However, less attention is paid to the sexuality of people diagnosed with intellectual disabilities. This narrative review summarises what is currently known about the level of sexual health knowledge of people with intellectual disabilities. A literature review was conducted of the published literature using Google Scholar, PubMed, PsychInfo, EBSCOhost, and Science Direct. Forty eight articles were identified that addressed the question about the level of sexual health knowledge of people with intellectual disabilities. Overall, studies demonstrate that people with intellectual disabilities are highly variable in levels of sexual knowledge, but on average have a range of deficits in knowledge compared to non-disabled individuals. More tailored education and support in accessing formal and informal sources of information are needed.

Keywords: intellectual disability, sexual knowledge, sex education, learning disability, sexuality.

There is a growing recognition that people with intellectual disabilities have the same sexual needs and rights as people without disabilities. The United Nations *Convention on the Rights of Persons with Disabilities* (UN, 2006) states that people with disabilities have the right to equal sexual and reproductive health rights and access to sexual and reproductive health care. However, as the first World Report on Disability published by the World Health Organisation (WHO) and the World Bank (2011) highlights, there are significant unmet needs when it comes to the sexual and reproductive health of people with disabilities. The WHO (2006) views sexual health as part of human development and human rights, and that if sexual health is to be attained, "the sexual rights of all persons must be respected, protected and fulfilled" (p. 5). However, there is a relative paucity of research on the sexuality and sexual health of people diagnosed with intellectual disabilities.

We have used the term intellectual disabilities in this paper (in the UK this is referred to as learning disabilities), as used in the Diagnostic and Statistical Manual of Mental Disorders (DSM-5; American Psychiatric Association, 2013) definition where intellectual disability is a term describing individuals who have general cognitive impairments that have an impact on adaptive functioning. There are four levels of intellectual disability: mild (IQ 50-70), moderate (IQ 35-49), severe (IQ 20-34) and profound (IQ below 20) (APA, 2013).

Available research shows that adults with intellectual disabilities, on average, not only present lower levels of knowledge than people without disabilities (e.g. Szollos & McCabe, 1995), but might also hold negative views towards sex (Bernert & Ogletree, 2012). At the same time, many people with intellectual disabilities have sexual needs and hope to be in a relationship (Froese, Richardson, Romer, & Swank, 1999; Kelly, Crowley, and Hamilton, 2009). Research shows that many individuals with intellectual disabilities, especially with mild impairments, are sexually active (McCabe, 1999; McGillivray, 1999). However, sex education is not always available (Milligan & Neufeldt, 2001; Rohleder & Swartz, 2012),

which may have many negative consequences, such as increased risk of sexually transmitted diseases (STD) (Aderemi, Pillay, & Esterhuizen, 2013). What is more, people with disabilities, especially children, are more vulnerable to abuse than their non-disabled peers (McKenzie & Swartz, 2011). Incidents of sexual abuse may go unreported due to a lack of sexual health education as well as other factors such as the attitudes of workers in protection, support and legal services towards the sexuality of people with intellectual disabilities (Meer & Combrinck, 2015). Finally, some authors suggest that deficits in sexual knowledge may lead to challenging behaviour, such as masturbating in public or invading other people's personal space (Grieve, McLaren & Lindsay, 2006; Timms & Goreczny, 2002).

Despite the fact that more and more carers and professionals believe that sex education is needed (Lafferty, 2012), many of them experience anxiety and ambivalence about discussing the topic of sexuality and relationships, often due to concerns about causing harm or beliefs that providing sex education will lead to inappropriate sexual behaviour (Rohleder, 2010). In a study conducted by de Reus, Hanass-Hancock, Henken and van Brakel (2015), educators working with disabled people recognised a number of challenges in their work, including barriers in communication and language, cultural values and expectations, learners' knowledge and behaviour, handling of sexual abuse cases and the teachers' own life experiences. In addition, many educators and teachers report being inadequately trained (Christian, Stinson & Dotson, 2001). Some parents of adolescents with intellectual disabilities have been found to be resistant to discussing sex with their offspring (Pownall & Jahoda, 2012).

As a precursor to identifying gaps in education, and responding to specified concerns by the UN (2006) and WHO (2006, 2011), information is needed on people with intellectual disabilities' knowledge about sex. The nature and extent of support required can best be determined through a careful assessment of the general level of knowledge. Details of

knowledge held is also important for the purpose of counselling or therapy, as well as when investigating potential cases of sexual abuse (Bell & Cameron, 2003). Swango-Wilson (2009) writes that education is a key to empower individuals to identify, report and prevent sexual assault and abuse.

The only other published review that looks at the level of sexual health knowledge amongst people with intellectual disabilities, as well as their needs, attitudes and feelings, was written by McCabe and Schreck (1992). Thus this review summarises what is currently known about the level of sexual knowledge among people with intellectual disabilities.

Method

This is a narrative review and as such it summarizes and critiques a body of literature. It has a broad research question, draws conclusions about the topic, identifies gaps, and does not use systematic criteria for appraisal. The search was conducted using the following electronic databases: Google Scholar, PubMed, EBSCOhost, PsychInfo and Science Direct. Key words included: sexual knowledge, learning disability, intellectual disability, mental retardation, mental handicap, cognitive disability, mental deficiency, mental disability, retarded, mentally retarded, mentally handicapped, autism, autism spectrum disorder, ASD, Down syndrome, Down's syndrome, Prader-Willi syndrome, Williams syndrome, Rett syndrome, Angelman syndrome, Angelman's syndrome, fragile X syndrome, Klinefelter's syndrome, congenital hydrocephalus, Smith-Magenis syndrome, fetal alcohol syndrome, foetal alcohol syndrome, 22q11 deletion syndrome. Articles were also identified from papers cited in the articles selected for inclusion in the review. The search was conducted between June 2013 and January 2014. The search was completed using many databases and a variety of key words, hence it is not possible to calculate the exact number of retrieved articles. As an example, search combination that brought the most findings (889 papers) in the Google

Scholar was ‘mental retardation & sexual knowledge’, whilst the same phrases in EBSCO Host were linked to 125 articles. In total, 48 articles were included. The inclusion criterion applied were: published papers, written in English and presenting original research specifically about intellectual disabilities and not disabilities in general. Included articles had to present data on the level of knowledge about sexuality and relationships in general or specific aspects of it, e.g. sexual abuse or sexually transmitted diseases. There were no criteria regarding the dates and only peer-reviewed papers were included.

O’Brien and Pearson (2004), in their review of the relationship between autism and intellectual disability, comment that even though there is no agreement on the exact prevalence rates of disabilities amongst people with autism, as many as 75 percent of individuals with autism may have an intellectual disability. Hence, research regarding individuals with autism is included in this review, with the exception of studies regarding individuals with high functioning autism (IQ $\geq$ 70).

Results

Forty-eight articles were identified that present original data and directly or indirectly assessed the level of sexual knowledge amongst people with intellectual disabilities and autism spectrum disorder. Two papers were case studies (Bell & Cameron, 2003; Shapiro & Sheridan, 1985). Therefore, it was decided that they would be excluded from the review as generalisation of findings would not be possible, leaving a total of 46 articles (see table 1).

In these articles, level of sexual knowledge was either the main objective of the study (e.g. Kijak, 2013; Leutar & Mihokovic, 2007), was measured as a part of the construction of a new tool (e.g. Galea et al., 2004; McCabe, 1999) or was measured as part of the evaluation of an intervention (e.g. McDermott, Martin, Weinrich, & Kelly,1999). In the majority of the studies, quantitative methods or mixed methods were used to collect data, with the exception

of Eastgate, Van Driel, Lennox, and Sheermeyer (2011), Healy, McGuire, Evans, and Carley (2009) and Kelly, Crowley, and Hamilton (2009) who used qualitative methods.

Twenty nine studies were conducted after 2000, which corresponds in time with an increasing emphasis in public policy on the civil rights, choice, independence and inclusion of people with intellectual disabilities (e.g. US Department of Health and Human Services, 2000; UK Department of Health, 2001). With regard to locality, 18 articles reported research carried out in Europe (9 in the United Kingdom, 4 in Ireland, 1 each in Croatia, Turkey, the Netherlands, and Poland), 13 in the United States of America, 9 in Australia, 3 in Canada, and 1 each in Nigeria, South Africa, Hong Kong, and New Zealand.

Sample sizes vary from 4 (Dukes & McGuire, 2009) to 300 participants (Aderemi et al., 2013), with the majority consisting of around 60 individuals. Samples were mainly drawn from special schools/educational settings (Aderemi et al., 2013; Bambury, Wilton, & Boyd, 1999; Brantlinger, 1985; Dawood, Bhagwanjee, Govender, & Chohan, 2006; Fischer & Krajicek, 1974; Gillies & McEwen, 1981; Hall, Morris, & Berker, 1973; Isler, Tas, Beytut, & Conk, 2009; Tang & Lee, 1999; Watson & Rogers, 1980) or institutions (such as residential settings and hospitals) (Edmondson, McCombs & Wish, 1979; Caspar & Glidden, 2001; Forchuk, Pitkeathly, Cook, Allen, & McDonald, 1984; Hall & Morris, 1976; Long, Krawczyk, & Kenworthy, 2011; Niederbuhl & Morris, 1993; Penny & Chataway, 1982; Siebelink, de Jong, Taal, Roelvink, 2006) or from offender populations (Lockhart, Guerin, Shanahan, & Coyle, 2010; Lunsky, Frijters, Griffiths, Watson, & Williston, 2007; Michie, Lindsay, Martin, & Grieve, 2006; Murphy, Powell, Guzman, & Hays, 2007; Talbot & Langdon, 2006). Only five studies recruited people living in the community (Garwood & McCabe, 2000; McCabe, 1999; McCabe & Cummins, 1996; Szollos & McCabe, 1995; Timmers, DuCharme, & Jacob, 1981). Thirty one articles report research using mixed or unspecified samples, 11 with mild, 3 moderate, and 1 severe intellectual disabilities.

Almost all studies examined the level of knowledge regarding sex and sexual health of people with intellectual disabilities. Three studies concerned people with autism, two of which compared people with autism and intellectual disabilities. No studies were found that reported research concerning people with genetic conditions such as Down Syndrome, Prader-Willi Syndrome or Williams Syndrome.

Summary of Levels of Sexual Knowledge

In general, studies found that sexual knowledge amongst people with intellectual disabilities is often lacking in certain areas, is inaccurate or contains misconceptions. However, there are considerable individual differences and variability in the level of knowledge (Brantlinger, 1985; Eastgate et al., 2011; Galea et al., 2004; Siebelink et al., 2006). In Edmonson and Wish's study (1975), the level of knowledge varied from 10% to 65% correct responses to a questionnaire and in Aderemi's et al. (2013) research about HIV awareness, level of knowledge about HIV transmission varied from 0 to 100% correct answers. Overall, the topic of body parts and physical characteristics appears to be the best understood, with birth control methods and STD's being the least understood. No further generalisations can be made.

Articles were grouped according to the level of disability of participants (mild, moderate and mixed or unspecified intellectual disabilities), as well as clustered into studies with participants with mean IQ at the level of 40, 50 and 60 scores. Comparisons were made between them to see if there was a link between the level of functioning and the level of knowledge, but no generalizable conclusions can be made. This somehow surprising result might be due to the factors such as lack of uniform terminology, use of poor quality assessment tools, scantiness or inadequacy of description of the samples used or/and results, differences in samples and methods. A key finding is that no obvious differences were observed between studies across the four decades in terms of overall knowledge, which appears to be consistently low. There has also been little change in terms of methods or samples used. This is surprising given that with deinstitutionalisation and supposedly improved sex education in schools, one would have expected a notable improvement in knowledge to be shown.

We had a look at levels of knowledge in specific areas.

Body parts and physical characteristics. Some studies report that participants present a sound knowledge of body parts and physical characteristics (Galea et al., 2004; Kijak, 2013; Lindsay, Bellshaw, Culross, Staines, & Michie, 1992; Lockhart, Guerin, Shanahan, & Coyle, 2010; Szollos & McCabe, 1995; Timmers et al., 1981) while others found low levels of knowledge in these areas (Bender, Aitman, Biggs, & Haug, 1983; Healy et al., 2009; Isler et al., 2009).

The difference in the above findings might be explained by several reasons. In the research conducted by Healy et al. (2009), only those under the age of 18 years had rudimentary knowledge about anatomy, older participants were well informed, which may suggest that young people with intellectual disabilities have gaps in knowledge about body parts, but the knowledge increases with the age. In Isler's et al. (2009) study, participants were asked about internal organs such as tubes, ovary, uterus, as well as external ones for example penis and vagina, which could lead to lower scores as the internal body parts might be less known to individuals with intellectual disabilities.

Sexual intercourse. Edmonson et al. (1979), Gillies and McEwen (1981), Hall and Morris (1976) and Timmers et al. (1981) found that their participants had good comprehension of sexual intercourse, while Bender et al. (1983), Isler et al. (2009), Jahoda and Pownall (2013) Kelly et al. (2009), McCabe (1999) and Szollos and McCabe (1995) obtained contrary results. There are no differences in methods and samples used in the studies that could explain these dissimilar results. It is also not clear from the papers if the topic of 'sexual intercourse' refers to general sexual activity between two people, or if it is specific to heterosexual penetrative sex.

Pregnancy. There is no agreement about the level of knowledge about pregnancy, with some research showing that individuals with intellectual disabilities present good knowledge about it (Edmonson et al., 1979; Galea et al., 2004; Hall & Morris, 1976; Leutar & Mihokovic, 2007; Timmers et al., 1981) and other that the level is low (Bender et al., 1983; Fisher & Krajicek, 1974; Kijak, 2013; Lindsay et al., 1992; McCabe, 1999). No differences in methods or samples used were noticed that could account for these contrary results.

Masturbation. Contradictory results were also achieved for the level of knowledge about masturbation. Edmonson and Wish (1979), Galea et al. (2004), Hall and Morris (1976), Leutar and Mihokovic (2007) and Timmers et al. (1981) found that the knowledge about masturbation was good, whilst Bender et al. (1983), Fisher and Krajicek (1974), Garwood and McCabe (2000), Healy et al. (2009), Isler et al. (2009), Szollos and McCabe (1995) found that it was low. When looking at the studies, nothing obvious was noticed that could explain these inconsistent outcomes.

Menstruation. Inconsistent results were also achieved in regards to knowledge about menstruation. Some authors found that the level of information was low (Galea et al., 2004; Garwood & McCabe, 2000- men only; Isler et al., 2009; Lockhart et al., 2010- men only; McCabe, 1999), whereas Hall and Morris (1976) and Leutar and Mihokovic (2007) that it was good. Again, there were no observable differences between the studies that could clarify the various results.

Legal aspects and social norms. Knowledge about the law on sexuality appears to be low. O'Callaghan and Murphy (2007) showed that adults with intellectual disabilities presented very limited understanding of the law, lower than control group consisting of younger participants, but with no intellectual disabilities. Galea et al. (2004) found that knowledge of illegal behaviour was good, but insufficient for the rights of people with disabilities. In three studies (Galea et al., 2004; Healy et al., 2009- only for individuals over

18 years old; Leutar & Mihokovic, 2007), participants showed good recognition of public/private spaces and in two sound knowledge of socially appropriate/inappropriate behaviour (Leutar & Mihokovic, 2007; Lockhart et al., 2010). However, Lockhart et al. (2010) concluded that participants appeared not to understand reasons why some behaviour was inappropriate.

Contraception and sexually transmitted diseases. Knowledge regarding contraception and STD's appears to be the most lacking (Bender et al, 1983; Edmonson et al., 1979; Galea et al., 2004; Gillies & McEwen, 1981; Hall & Morris, 1976; Kijak, 2013; Leutar & Mihokovic, 2007; Lindsay et al., 1992; Lockhart et al., 2010), with the exception of the study conducted by Timmers et al.(1981), which found that most of the individuals had good knowledge about venereal diseases and all participants knew about contraception. However, the results achieved by Timmers et al. (1981) might be due to the scoring method used by the authors. Participants were assessed to have a good knowledge if they could name one method of contraception. Hence, all 25 participants were described as knowledgeable on how to prevent pregnancy. In other studies, such as Kijak's (2013), participants needed to name at least three methods of contraception in order to be classified as being well informed in this area. Also, in Timmers' et al. (1981) study, if participants were aware that venereal diseases were contracted through sexual contact, they were assessed as having good knowledge. In other studies, for example one by Leutar and Mihokovic (2007), participants were asked a number of questions about STD's, such as ways of transmission, prevention, their names etc. in order to fully assess information they had about it.

The four studies investigating the level of knowledge of people with intellectual disabilities regarding HIV/AIDS (Aderemi et al., 2013; Dawood et al., 2006; Delaine, 2013; McGillivray, 1999) showed deficits in knowledge, especially about transmission and cure of

HIV/AIDS. However, Delaine (2013) demonstrated that knowledge could be improved by training.

Factors Related to Sexual Knowledge

Differences in the level of knowledge might be due to many factors. The main reason is that people with intellectual disabilities are a very heterogeneous group and live in environments with varying levels of social restrictions. Additionally, there is diversity across different areas of the world about how intellectual disabilities should be labelled and this review used a variety of search terms. In Europe and much of Australasia, the term 'intellectual disabilities' is often used differently in educational and other contexts, and which can include specific learning disabilities, intellectual disabilities and pervasive developmental disorders, whilst in the USA phrase 'developmental disabilities' is a broad, umbrella term to refer to intellectual disabilities and pervasive developmental disorders (Davey, 2008). Some studies, therefore, might report on a mixed group of people, some of whom may not fall into the current category definitions of having 'intellectual disabilities'.

Individual studies show that general intelligence is positively related to levels of knowledge (Edmonson & Wish, 1975; Hall et al., 1973; Konstantareas & Lunsky, 1997; Leutar & Mihokovic, 2007; Michie et al., 2006; O'Callaghan & Murphy, 2007; Ousley & Mesibov, 1991). However, it is not clear how much the better performance of people with milder impairments is due to better communication and reading skills and how much to greater knowledge levels (Talbot & Langdon, 2006). The better performance of people with higher levels of functioning might also be due to better access to sex education, especially if they attend mainstream schools, where they have access to more extensive and intensive sex education.

Hall and Morris (1976) suggest that years of institutionalisation have an impact on the level of knowledge, with those who have been institutionalised for some years having less

sexual knowledge than those who have not. Similarly, Robinson (1984) found that community based participants were more knowledgeable than those living in an institution. However, in a study conducted by Edmondson and Wish (1975) there was no correlation between years of institutional residence and correct responses.

Many authors (e.g. Lindsay et al., 1992; Penny & Chataway, 1982) showed in their research that there was a significant and substantial increase in sexual knowledge after receiving sex education. Some researchers suggest that the effects of receiving sex education may be short term, not only due to cognitive abilities, but also because of the lack of ability to transfer knowledge obtained during the training into the real life situations (O'Callaghan & Murphy, 2007). However, research conducted by Delaine (2013), Dukes and McGuire (2009), McDermott et al. (1999), Murphy et al. (2007), Robinson (1984) show that increases in knowledge were observed after taking part in training and on follow-up (post- tests completed between 3 weeks to a year after the intervention or baseline assessment). In the study conducted by Penny and Chataway (1982), the level of knowledge continued to increase between post-test completed shortly after completion of sex education and post-test done 2 months later despite no intervention during that period. The authors suggest that it may be due to informal learning occurring by sharing of information amongst participants who formed friendships during the sex education course.

Neither age nor gender seems to have an impact on the level of knowledge (Galea et al., 2004; Konstantareas & Lunsky, 1997; Leutar & Mihokovic, 2007; McGillivray, 1999; Ousley & Mesibov, 1991; Siebielink et al., 2006). Only four articles showed sex differences. In three studies, men with intellectual disabilities were found to be more knowledgeable than women (Aderemi et al., 2013; Jahoda & Pownall, 2013, Penny & Chataway, 1982) and in one paper women had higher levels of knowledge than men (Szollos & McCabe, 1995).

It is not clear whether sexual experience is associated with sexual knowledge. Michie et al. (2006) found that sexual offenders with intellectual disabilities had higher levels of knowledge than non-offenders. According to the authors, it can be assumed that sex offenders had some experience of sexual activity, which cannot be presumed with the control participants. Other offender studies did not show a difference. Additionally, Ousley and Mesibov (1991) found no correlation between experience and level of knowledge amongst people with "developmental delay" and autism.

In regards to a link between the nature of the diagnosis and level of knowledge, conclusions cannot be drawn as only three studies recruited individuals with autism, two of which compared the level of knowledge about sexuality between autistic participants and those with intellectual disabilities and found no difference (Ousley & Mesibov, 1991; Konstantareas & Lunsky, 1997). No studies were found regarding other diagnoses.

Factors related to limited knowledge might be problems with communication and limited reading ability (Tang & Lee, 1999). However, much of this may be down to social exclusion. Some knowledge regarding relationships comes not from formal sources, such as school, but rather informal sources such as friends and social networks. People with intellectual disabilities generally have much smaller social networks. For example, in Pownall and Jahoda's research (2013) disabled young people reported less formal and informal sources of sexual information and described smaller social networks than their non-disabled peers. What is more, individuals with intellectual disabilities have much more restricted access to the types of leisure activities where people would exchange information pertaining to sexuality. Nowadays, digital exclusion of some people with intellectual disabilities may also play a role in their limited knowledge.

Consequences of Limited Knowledge

There are many possible consequences of low levels of sexual knowledge amongst people with intellectual disabilities. It is suggested that inadequate and incomplete knowledge might be contributing to the fact that people with intellectual disabilities are at greater risk of abuse (Hall & Morris, 1976; Tang & Lee, 1999; Turk & Brown, 1993) and may increase risk of having STD's (Aderemi et al., 2013, McGillivray, 1999) and unplanned pregnancies (Cheng & Udry, 2005). Shapiro and Sheridan (1985) imply that limited knowledge of reproductive health care may lead to higher occurrence of undetected cancer amongst women with intellectual disabilities. However, no empirical evidence is presented for any of the above suggestions.

Some authors suggested that limited sexual knowledge might possibly account for the sexual offences of some people with ID (Barronet, Hassiotis, & Banes, 2002). However, Talbot and Langdon (2006), Lunsky et al. (2007), Lockhart et al. (2010) and Michie et al. (2006) demonstrated in their research that offenders present the same or even higher levels of knowledge that people with no known history of sex offending. Timms and Goreczny (2002) suggested that lack of knowledge, especially regarding social norms, may lead to challenging behaviour, such as masturbation in public or invasion of other people's personal space. To date, no clear evidence is available on this possibility.

Finally, Dukes and McGuire (2009) and Niederbuhl and Morris (1993) showed in their research that the higher the level of knowledge, the greater the capacity to make sexuality- related decisions. Hence, people with limited knowledge, might not be able to make informed choices whether to consent to sexual behaviour or not.

Evaluation of Methods and Tools Used

The only observable change in methods over the four decades of the review is an increase in using qualitative methods after 2000. Samples in all studies were drawn by different means. For example in some of the studies participants were chosen by service managers (McGillivray, 1999; Penny & Chataway, 1982) or by a psychologist (Lockhart et al., 2010), which could result in the selective assessment of those with better communication skills and a pre-existing interest in sexual issues. Furthermore, none of the studies report findings on representative groups of people, as most used convenience sampling within a specific institutional or organisational setting. It is also worth noting that 11 studies had 25 or fewer participants with intellectual disabilities (Bambury et al., 1999; Brantlinger, 1985; Caspar & Glidden, 2001; Delaine, 2013; Dukes & McGuire, 2009; Eastgate et al, 2011; Garwood & McCabe, 2000; Kelly et al., 2009; Leutar & Mihokovic, 2007; Murphy et al., 2007; Szollos & McCabe, 1995), which makes generalisation difficult.

Most of the researchers administered their questionnaires in a form of interview. However, it is unclear in some of the articles how the knowledge was assessed (e.g. Bender et al., 1983), which may mean that some of the information was obtained using 'pen and paper' method, which could lead to non-generalizable results, as only those who were able to write and were better functioning were included.

In the majority of studies researchers used questionnaires developed for the particular study, with no or little attention paid to psychometric properties (Bender et al., 1983; Brantlinger, 1985; Caspar & Glidden, 2001; Hall et al., 1973; Isler et al., 2009; Penny & Chataway, 1982; Timmers et al., 1981). Other measurements, that had reliability and validity assessed, and sometimes were used in more than one projects, are listed and evaluated in table 2. The authors of this review relied on information regarding reliability / validity of the

tools provided by the studies. All the tools presented were specifically developed or adapted (e.g. Sex-Ken) and evaluated in populations with intellectual disability.

General Methodological Issues

Apart from a tendency not to provide evidence of the reliability and validity of measures (described above), there are many general difficulties in assessing sexual knowledge in this population. Certain questions may be too difficult for people with intellectual disabilities to understand, especially if they use medical or formal terms. For example, Bender et al. (1983) found in their study that some of the participants did not know the word 'masturbation', but when the question was rephrased and they were asked about 'playing with yourself', they knew the answer. Additionally, some of the comprehensive measures are lengthy. For example, the Sex-Ken scale (McCabe et al., 1999; McCabe, 1999; McCabe, 2010) contains 248 questions, taking an hour to complete as a questionnaire and up to 3 hours if completed as an interview. Siebelink et al. (2006) suggest that the assessment should take no longer than 30 minutes. Some people with intellectual difficulties may experience problems with memory and recalling information. Furthermore, all of the available tools are suitable only for people who communicate using speech.

Every self-report measure has limitations in terms of reliance on the respondents' honesty, accuracy and their readiness to disclose information that may be seen as socially undesirable (Catania, Gibson, Chitwood, & Coates, 1990; Heiman, Meston, Paulhus, & Trapnell,1998). Galea et al. (2004) suggest that since research on sexuality contains sensitive material, it can be difficult to recruit participants. Some authors (Helleman, Colson, Verbraeken, Vermeiren, & Deboutte, 2007; Ruble & Dairymple, 1993) chose to base their research on the estimation of proxies (e.g. parents) instead of actual individuals with intellectual disabilities or high functioning autism. One main concern is that people with difficulties and/or their parents might be reluctant to consent to take part in sexuality related studies, because it may upset them or trigger disruptive behaviour (Ousley & Mesibov, 1991). However, Thomas and Kroese (2005) demonstrated in their research that there were no

negative consequences of taking part in sexuality research and no increase in sexual behaviour or talk.

In the situation where participants are below 16 or 18 years old (depending on the law on age of consent in particular countries) or if they are found to be incapable of making decision themselves, consultation with the parents/guardians is required. This might result in people who would be willing to participate being excluded. On the other hand, those who come from families where sexuality is not a taboo topic, and who might therefore achieve higher scores on sexuality knowledge measures, might be over-represented.

Recommendations for Research and Policy

Studies have clearly established the fact that the level of knowledge is generally low. However, we need to know more about how this translates into practice. We also need more information, for example about prevalence of unsafe/safe sex practice and various factors that may affect level of knowledge.

The majority of studies have concentrated on people with mild to moderate intellectual disabilities. Far less is known about the sexuality of people with profound/ multiple disability or those, who are not able to communicate verbally. More research is needed regarding specific genetic conditions, such as Prader-Willi syndrome, Williams syndrome or Angelman syndrome. We also need to know more about the interaction between disability and demographics such as gender, sexual orientation, and religion, as well as the effects of stigma and social isolation.

Several areas are worth further investigation. Research is particularly needed exploring sexual health issues across the lifespan, including children, adolescents, adults and older adults. More research is needed in places such as Africa, Asia and South America, as currently most of available research has been done in Europe, North America and

Australasia. Given the risk for HIV among people with disabilities in some of these less resourced areas of the world (see Groce et al., 2013), this is of great importance. More attention should be paid to the topic of pregnancy and reproduction, as they seem to be under-researched. Finally, we need more evidence on the psychometric properties of the tools to measure levels of knowledge, with development of tools that can be used with people communication in different ways, other than speech.

This review suggests several policy recommendations. Better training and support for teachers is needed to reduce their anxiety about delivering sex education. Sexual health education has to be included (where it is not) in all school curricula, it should be tailored to the needs of learners, and education and support must be available after leaving school. It is clear from research that teaching people with intellectual disabilities is the most effective when information is repeated several times, and this points to a collaborative approach between various stakeholders to ensure education takes place at school and at home.

Summary

Given the diverse range of studies, sample populations, constructs and measures used, we did not conduct a meta-analysis or systematic review, but rather a critical narrative review. We acknowledge that to a certain extent this can be subjective in the determination of which studies to include, the way the studies are analysed, and the conclusions drawn. We also acknowledge that further critique could have been made between study characteristics and study results, but we chose to concentrate primarily in reviewing level of knowledge and the instruments used.

Studies demonstrate that people with intellectual disabilities are highly variable in levels of sexual knowledge, but on average have a range of deficits compared to non-disabled individuals. Comprehensive sex education, tailored to the needs of participants is therefore

needed (McCabe, 1999). Overall, body parts and physical characteristics appear to be best understood, and birth control and STD's the least.

The assessment of knowledge is important so that the most appropriate and relevant materials can be included in sex education programs. However, as McGillivray (1999) points out although knowledge is an important factor in health- enhancing behaviour (such as safer sex practices), beliefs, attitudes and confidence need to be taken into consideration when planning interventions.

Compliance with Ethical Standards

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Table 1
Papers regarding sexual health knowledge of people with intellectual disabilities

Authors, year and location	**Sample**	**Method**	**Key Results**
Aderemi, Pillay, Esterhuizen (2013) Nigeria	300 participants (123 females), mean age=16.3, with mild/moderate intellectual disabilities; and 300 without disabilities (154 females), age range 12 to 19.	Structured questionnaire.	Diagnosis of ID was significantly associated with lower HIV transmission knowledge (mean score = 52.85 comparing to M=70.44 for non-disabled students); level of knowledge about HIV transmission varied; male adolescent with ID were more knowledgeable than females with ID; learners with intellectual impairments had less access to sources of HIV information.
Bambury, Wilton, Boyd (1999) New Zealand	18 adults (3 females), age range 17-46 with mild intellectual disability.	SSKAT (Wish et al., 1977).	Significant increases in knowledge of the students following educational program.
Bender, Aitman, Biggs, Haug (1983) UK	15 “hard-core” delinquents (mean age= 16) and 18 severely “mentally	Questionnaire developed by authors	Adolescent boys more knowledgeable than “mentally handicapped” adults; individuals in both group ignorant regarding physiology and venereal disease; adults with mental handicap also presenting ignorance in the area of

Authors, year and location	Sample	Method	Key Results
	handicapped [a]" young adults, mean age= 24; no exact information on range of IQ.	administered pre- and post-education.	contraception; disabled group showed increased sexual knowledge after a human relations course; no relation between age and knowledge.
Brantlinger (1985) USA	13 adolescents with mild "retardation" (5 females), mean age= 15.7.	Interview questionnaire developed by the author.	Broad range in levels of information about sexuality; participants confused about birth control; 46% correct answers for knowledge on pregnancy; majority were uninformed and/or misinformed.

[a] We use the specific terms used in the original articles. While many are no longer used or considered unacceptable now, it would be inaccurate to replace them with current terms as diagnostic criteria have changed over the years.

Authors, year and location	Sample	Method	Key Results
Caspar, Glidden (2001) USA	12 adults (9 females) who received sex education, mean age=38; 6 people with mild "mental retardation" and 6 with moderate.	Pencil and paper test written by the authors.	Of 16 possible points, the pre-test M=9, post-test M=12.9; all but one participants showed improvements.
Dawood, Bhagwanjee, Govender, Chohan (2006) South Africa	90 Adolescents (23 females), 14 to 16 years old, with mild "mental retardation".	Questionnaire developed by authors	78% of participants aware of STD's and 86% of HIV/AIDS; 57% of learners believed that HIV infection results in AIDS; some erroneous beliefs regarding transmission of HIV and cure for HIV.
Delaine (2013) USA	A convenience sample of 25 women (age 24 to 59) with mild to moderate intellectual disabilities (IQ ranging from 55 to 75).	Pre-and post-training qualitative interview and	Except for one domain (identification of high-risk fluids) all participants showed significant gains in both HIV knowledge and condom application skills after training.

Authors, year and location	Sample	Method	Key Results
		Audio Computer Assisted Self-Interview.	
Dukes, McGuire (2009) Ireland	2 men and 2 females with a moderate intellectual disability aged 22 and 23 years old.	The Sexual Consent and Education Assessment (Kennedy, 1993).	All participants improved their knowledge after education and as a result sexuality related decision making capacity; six month follow- up data for 3 of 4 individuals showed maintenance of scores on safety practices scores and some decay of knowledge scores.
Eastgate, Van Driel, Lennox, Sheermeyer (2011) Australia	9 women with mild intellectual disabilities; participants were aged 21-46 years.	Semi- structured interviews.	Participants understanding of sexual intercourse varied from very simplistic, with no apparent understanding of the process of sexual intercourse to a broad, sophisticated understanding of sexuality; participants could identify some form of sexual activity other than penetrative intercourse, but struggled to outline a progression from touching or kissing to penetrative intercourse.

Authors, year and location	Sample	Method	Key Results
Edmonson, Wish (1975) USA	18 moderately "retarded" males, aged 18-30 years old; IQs from 30 to 55.	Semi structured interview with pictures developed by authors.	Level of knowledge varied from 10 % to 65% correct responses; 1/3 of participants knew about pregnancy and childbirth and half knew about masturbation; overall some understanding of human anatomy and sexual activity, but many errors.
Edmonson, McCombs, Wish (1979) USA	99 institutionalised adults (50 females); age 18 to 42, IQs from 27 to 74; 100 adults living in community (50 females), aged 18 to 42, IQs from 23 to 70.	Socio-Sexual Knowledge and Attitudes Test SSKAT (Wish, et al. 1977).	Good knowledge about anatomy, dating, marriage, intercourse (69%-70% of correct answers); the responders were least knowledgeable about birth control, venereal disease and homosexuality.

Authors, year and location	Sample	Method	Key Results
Fischer, Krajicek (1974) USA	16 moderately "retarded" adolescents (8 females); age 10-17 years old; mean IQ= 46.8.	Interviews based on structured questionnaire and visual materials.	Participants not able to verbalise appropriate names for sexual body parts; term 'masturbation' absent for all children; 81% to 94% correct answers for identifying pictures of hugging, kissing and intercourse; meagre knowledge of pregnancy.
Forchuk, Pitkeathly, Cook, Allen, McDonald (1984) Canada	42 "mentally retarded" participants with behavioural and/or psychiatric problems staying in hospital; maximum IQ= 68; aged 16 to 65 years.	Verbal test administered pre- and post-education.	About half of the participants knew one method of contraception comparing to over 70% after the course; 11 people could give accurate answer on what sex or sexual intercourse means before the training, comparing to over half of the participants after.
Galea, Butler, Iacono, Leighton (2004) Australia	96 adults with mild (75% of the sample) and moderate intellectual disability (42 females), mean age=31.5.	Questionnaire: Assessment of Sexual	Relatively good knowledge of body parts, public and private parts and places, masturbation, relationships, protective behaviour, pregnancy and birth, and illegal sexual behaviour; low levels of knowledge on puberty, menstruation,

Authors, year and location	Sample	Method	Key Results
		Knowledge (ASK).	menopause, sexuality, safer sex practices, sexual health, STD, sexual rights, and contraception; no gender differences in knowledge (except for menstruation).
Garwood, McCabe(2000) Australia	6 men with mild intellectual disabilities, who took part in training.	Sex-Ken questionnaire (McCabe, 1993).	Low levels of knowledge about masturbation and menstruation before and after training; improvements in knowledge of friendship, contraception, pregnancy, sexual interaction and social skills in post-test.
Gillies, McEwen (1981) UK	79 “mildly subnormal” students from special schools and 475 pupils from ordinary secondary schools; ages 14 and 16 years old.	Questionnaire developed by authors.	“Mildly subnormal” students had significantly lower levels of sexual knowledge, particularly in the areas of menstruation, venereal diseases and abortions; both groups lacked knowledge of contraception; no age differences; majority of “mildly subnormal” participants had good comprehension of sexual intercourse.

Authors, year and location	Sample	Method	Key Results
Hall, Morris, Barker (1973) USA	56 "mentally retarded" participants and 5 with learning disabilities (30 females); mean IQ= 66.6; mean age= 17.7.	Questionnaire constructed by authors.	Responses correct on over half of the questions on the knowledge questionnaire; lack of accurate information on conception, contraception and venereal disease; people with higher IQ, mental age and chronological age tended to have higher scores on knowledge.
Hall, Morris (1976) USA	61 institutionalised young people (30 females), mean age= 17.3, mean IQ= 63.6; and 61 non-institutionalised adolescents (30 females), mean age= 18.3, mean IQ= 67.3.	Instrument created by authors.	Institutionalised adolescents had considerably less knowledge; both groups could identify what masturbation, menstruation, pregnancy and sexual intercourse were, but less than half of participants knew what venereal disease, family planning and birth control were.
Healy, McGuire, Evans, Carley (2009) Ireland	32 participants (12 females); aged 13 to 31; severity of disability not specified.	Focus group interviews.	Participants under the age of 18 years had only rudimentary knowledge of sexuality issues (e.g. pregnancy, contraception, STD's and sexual anatomy); all individuals had rudimentary or incorrect knowledge about masturbation; older participants (over 18) understood the private/public concept and most of them had knowledge of contraception.

Authors, year and location	Sample	Method	Key Results
Isler, Tas, Beytut, Conk (2009) Turkey	60 students with mild and moderate intellectual disabilities; aged 15-20 years old.	Questionnaire developed by researchers.	Very low levels of knowledge about sex and the characteristics of sexual development in adolescence; low level of knowledge about sexual intercourse, masturbation and menstruation.
Kelly, Crowley, Hamilton (2009) Ireland	15 participants (7 females), ranging in age from 23 to 41 years; no data on severity of learning disability.	Focus group interviews.	Sexual knowledge was limited; three individuals who had received formal sex education had understanding of sexual intercourse, procreation, contraception and STD's, the remaining participants (three quarters of the sample) had limited level of knowledge.
Kijak (2013) Poland	133 participants (42 females) with "higher degree" of intellectual disabilities, aged 18-25.	Structured interviews.	89% of participants had very good knowledge about their own sex physical characteristics and 77% about the characteristics of opposite sex; 52% could correctly describe how a baby is conceived; low levels of knowledge about pregnancy, childbirth, and contraception.

Authors, year and location	Sample	Method	Key Results
Konstantareas, Lunsky (1997) Canada	31 individuals age 16-46 years, 15 with autistic disorder (6 females) and 16 with developmental delay (8 females); two thirds of the participants fell into mild "retardation" range and one third moderate to severe.	Specially constructed questionnaire: Socio-Sexual Knowledge, Experience, Attitudes and Interests.	Almost all participants knew gender labels and pregnancy, but only 56% could explain how a woman gets pregnant and 16% knew the term 'ejaculation'; knowledge was no different by level of functioning, group or gender.
Leutar, Mihokovic (2007) Croatia	24 adults (10 females), aged 19 to 53; 18 participants with mild mental disability and 6 with moderate.	Questionnaire created by authors administered as an interview.	Good knowledge of differences between genders and pregnancy; relatively good knowledge in distinguishing between appropriate and inappropriate ways of sexual behaviour and social understanding of situational forms; low levels of knowledge in the area of STDs and methods of protection; overall level of knowledge was insufficient.

Authors, year and location	Sample	Method	Key Results
Lindsay, Bellshaw, Culross, Staines, Michie (1992) UK	2 groups with mild or moderate intellectual disabilities; group one: 46 adults (mean age= 28.7) who participated in sex education; group two: 14 individuals (mean age= 26.2) who did not receive sex education; mean IQ = 58.	Questionnaire designed by Fisher (1973), administered pre- and post-education.	The mean number of correct answers for masturbation, puberty, intercourse, pregnancy and childbirth was around 30%- 40%; only 20% for birth control and less than 5% for venereal disease; the group receiving sex education improved their knowledge significantly; the improvements maintained to a 3-month follow-up.
Lockhart, Guerin, Shanahan, Coyle (2010) Ireland	3 groups of 8 people in each (7 males) with mild and moderate intellectual disabilities: (1) group of people with sexualised challenging behaviour (2) group with non-sexualised challenging behaviour and (3) group of individuals	SSKAT-R (Griffiths & Lunsky, 2003).	All participants showed good knowledge of body parts names; higher knowledge for lower intimacy behaviour, such as hand holding and kissing; lower level of knowledge of pregnancy, childbirth and childrearing; lowest scores were achieved in relation to birth control and STDs; socio-sexual boundaries were an area of relatively high knowledge with all groups; no significant group effect was observed for sexual knowledge.

Authors, year and location	Sample	Method	Key Results
	with no challenging behaviour; age range 25-65 years old.		
Long, Krawczyk, Kenworthy (2011) UK	16 women in secure psychiatric facility for patients with a combination of learning disability, mental illness and personality disorder; 13 had a mild to moderate learning disability.	St Andrews Sexual Knowledge and Attitudes Instrument developed by authors.	All participants had difficulties with the names and functions of internal body parts; 56.3% of the sample had a very limited knowledge of STDs.
Lunsky, Frijters, Griffiths, Watson, Williston (2007) Canada	48 men with an ID with sexual offence history and 48 men with ID with no known sexual offence history; age range from 16-71 years (mean =37);	The Socio-Sexual Knowledge and Attitudes Assessment Tool	Participants with offense history did not differ in terms of sexual knowledge from their matched sample of individuals without sexual offence history; offenders who had committed more serious offences (e.g. paedophilia) demonstrated greater sexual knowledge than matched non-offenders; when

Authors, year and location	Sample	Method	Key Results
	borderline IQ (19%) to mild (61%), moderate (16%) and severe (4%).	Revised SSKAT-R (Griffiths & Lunsky, 2003).	those individuals who had received prior sex education were compared, there were no differences in knowledge between groups.
McCabe, Cummins (1996) Australia	30 participants (18 females) with mild intellectual disability, mean age=25.2; control group of 50 students (32 females), mean age=20.6.	Sex-Ken questionnaire (McCabe, 1993).	People with ID demonstrated lower levels of knowledge that participants from control group on all subscales, except for body part identification and menstruation where there was no difference between groups.
McCabe (1999) Australia	60 people with mild intellectual disability (32 females), mean age= 27.62; 60 people with physical disability (27 females), mean age= 28.65; and 100 people from the general population (60 females), mean age= 30.10.	Sex-Ken (McCabe, 1993).	People with IDs presented lower levels of sexual knowledge and experience, more negative attitudes to sex and stronger sexual needs that people with physical disabilities, who in turn had lower levels of knowledge compared to people from the general population; participants with ID's had poor knowledge about contraception; STD's; sexual interaction; menstruation; 30% correct answers for pregnancy/childbirth and masturbation.

Authors, year and location	Sample	Method	Key Results
McDermot, Martin, Weinrich, Kelly (1999) USA	252 women (average age 31.9 years) with mild "mental retardation"; mean IQ score= 59.9.	Social Sexual Assessment (no information about the author).	Statistically significant positive change after sexual education for sexual knowledge; hygiene, social interactions and sexual experience affected sexual knowledge.
McGillivray (1999) Australia	60 adults (25 females), aged 18-59 years, with mild/moderate intellectual disability; and 60 undergraduate students (25 females), aged 13 to 31.	Instrument developed by author.	Participants with ID had deficits in their general knowledge of AIDS and in methods to minimise risk of infection; when presented with hypothetical risk situations they were more likely to present unsafe sexual solutions to the interpersonal dilemmas than non-disabled students.
Michie, Lindsay, Martin, Grieve (2006) UK	Cohort 1: 17 male sex offenders (mean IQ= 66, mean age= 34) and 20 males with no history of inappropriate sexual	SSKAT (Wish et al., 1977).	The sex offenders had the same or greater level of knowledge than control group; highly significant correlation between IQ and sexual knowledge for non-offenders and no significant correlation for sex offenders.

Authors, year and location	Sample	Method	Key Results
	behaviour (mean IQ= 63, mean age= 33); cohort 2: 16 male sex offenders (mean IQ= 66, mean age= 34) and 15 non- offenders (mean IQ= 66, mean age= 30).		
Murphy, Powell, Guzman, Hays (2007) UK	8 men with intellectual disabilities (mean IQ=67) referred for treatment for sexually abusive behaviour.	Sexual Attitudes and Knowledge Scale (author unknown).	Mean level of knowledge increased from M= 39.5 pre-group to M=44.7 post-group.
Niederbuhl, Morris (1993) USA	32 participants (16 females); aged 21 to 65; 20 individuals had mild "mental retardation", 6 moderate, 5 severe and 1	SSKAT (Wish, et al. 1977); capability	Capability status correlated strongly with knowledge scores, with level of mental retardation, with completion of the sex education course; participants ranged in their answers on SSKAT from 20% correct answers to 98%.

Authors, year and location	Sample	Method	Key Results
	borderline; 26 people also had diagnosis of psychiatric condition.	assessed by professionals.	
O'Callaghan, Murphy (2007) UK	60 adults with an intellectual disability (ID), aged 21 to 62 years, mean IQ= 59.8; 60 people aged 16- 18 years without intellectual disabilities.	Questionnaire developed by authors to assess understanding of sex and the law.	Adults with ID had a very limited understanding of the general laws relating to sexuality (e.g. age of consent, incest, abuse) as well as the law relating to sexuality of people with IDs (e.g. whether they could have sexual relationships, if they were allowed to marry); young people without ID's were more knowledgeable.
Ousley, Mesibov (1991) USA	21 people with high functioning autism (10 females); mean IQ = 79.15, mean age= 27 years; and 20 people with learning disabilities (10 females); mean IQ= 55.75, mean age= 27.	Interview questionnaire constructed by authors.	Positive correlation between IQ and knowledge score; knowledge was not correlated with interest or experience; no group difference in knowledge; participants with autism had significantly less experience with sexuality than those with learning disability.

Authors, year and location	Sample	Method	Key Results
Penny, Chataway (1982) Australia	44 participants with mild and 5 with moderate "retardation" (21 females); mean age=22yrs.	Especially constructed sex vocabulary test administered pre- and post-education.	Women scored lower, but difference did not reach significance; all participants showed increases in knowledge between pre-test and post- test of knowledge following an educational intervention.
Robinson (1984) Australia	83 participants, IQ between 50 and 80, aged 16 to 52; 41 participants attended sex education program, remaining participants acted as a control.	SSKAT (Wish, et al., 1977).	No difference in knowledge between sexes; community based individuals more knowledgeable than institutionalised before the sex education; all experimental participants showed improvement in knowledge.
Ruble, Dairymple (1993) USA	Survey of 100 parents of individuals with autism, 84% of people within "mental retardation" range; age range 9 to 38 years old.	Sexuality Awareness Survey developed	Caregivers responded that 47% of people with autism had knowledge of body parts and functions, 51% understood public/private behaviour, 45% received sex education which was effective for 71% of individuals.

Authors, year and location	Sample	Method	Key Results
		using a sample of 10 parents.	
Siebelink, de Jong, Taal, Roelvink (2006) The Netherlands	76 participants (29 females); 56 with mild, 4 moderate, 11 borderline intellectual disabilities (IQ of 5 individuals was unknown); 18 participants were less than 30 years old, 40 participants between 30 and 50, and 18 older than 50.	Structured interviews using questionnaire created by authors.	Some knowledge, but far from exhaustive; big individual differences; no differences between gender and age group; people with more sexual knowledge had more positive attitudes.
Szollos, McCabe (1995) Australia	25 participants (15 females); mean age=25.2 with mild intellectual disabilities; control group of 39 students (29 female), mean age=22.5.	Sexual Knowledge, Experiences and Needs Scale Sex-	Highest scores amongst people with intellectual disabilities (ID) for body part identification; least knowledge about STD's and sexual interaction; overall low levels of knowledge; students showed greater knowledge than people with ID in all but two areas: body part identification and dating and intimacy.

Authors, year and location	Sample	Method	Key Results
		Ken (McCabe, 1993).	
Timmers, DuCharme, Jacob (1981) USA	25 adults with mild "retardation" (12 females); mean age= 28.3.	Questionnaire constructed by authors, administered as an interview.	Very good knowledge of body parts; all participants knew about dating, pregnancy and contraception; most of the individuals had knowledge about venereal diseases.
Tang, Lee (1999) Hong Kong	77 females (aged 11 to 15 years) with mild "mental retardation".	Personal Safety Questionnaire (Wurtele, 1990) and the "What if" Situation Test (Wurtele, 1990).	Participants possessed limited information about sexual abuse; sexual knowledge was the best predictor of ability to mobilize self-protection skills.

Authors, year and location	Sample	Method	Key Results
Talbot, Langdon (2006) UK	4 groups of participants: 1) sex offenders with an intellectual disability (ID), who did engage in treatment (n=12; mean IQ = 64.9), 2) sex offenders with an ID and no history of treatment (n=13; mean IQ=62.4), 3) non-offenders with an ID (n=28), 4) non-offenders without an ID (n=10);	Updated version of Bender Sexual Knowledge Questionnaire (Bender et al., 1983).	Participants without ID scored significantly higher that people with an ID; sex offenders with an ID who had undergone treatment scored higher than those who had not receive treatment; assumption that lower sexual knowledge may be related to the risk of committing a sexual offence has not been proven.
Watson, Rogers (1980) UK	194 mildly "educationally subnormal students" (96 female), mean age= 14.5; 61 children from comprehensive school as a control group.	Instrument constructed by authors for the study.	Mildly "educationally subnormal students" having less knowledge than students from control group; students from special school had some basic knowledge.

Table 2

Review of tools measuring sexual health knowledge

Questionnaire	**Areas assessed**	**Reliability, validity, and evaluation**
Assessment of Sexual Knowledge (ASK) (Galea, Butler & Iacono, 2003)	Consists of knowledge section, an attitudes section (no scoring for attitudes), problematic socio-sexual behaviours checklist and a Quick Knowledge Quiz version that can be used when the knowledge section cannot be administered (for example because of time constraints or communication difficulties) - 25 items 'yes' or 'no' response; the knowledge section divided into 15 topics: parts of the body, public and private, puberty,	Completion time about 45 min; authors report "high level of test- retest reliability" (no numbers provided); good tool to assess baseline knowledge prior to education programme and upon its completion; according to authors it has "good inter-rater reliability" (no numbers provided); ASK is only suitable for people who communicate using speech; validity "not possible to assess due to limited number of tools"; Quick

Questionnaire	Areas assessed	Reliability, validity, and evaluation
	menstruation, menopause, masturbation, relationships, protective behaviours, sexuality, safer sex practices, contraception, pregnancy & birth, sexual health – screening tests, STD's, legal issues regarding sexuality; responses in the knowledge section are scored as 0 for incorrect, 1 for partially correct and 2 for correct; each question is followed by specific prompt; the attitudes section consist of questions how a person feels about a particular subject.	Knowledge Quiz is a predictor of knowledge scores in the ASK, but is recommended rather as a an initial screening tool and not to replace a comprehensive assessment (Galea, Butler & Iacono, 2003).
General Sexual Knowledge Questionnaire (GSKQ) (Talbot & Langdon, 2006) – revised and updated version of	Consists of 63 items divided into six sections: physiology-pictures and questions, sexual intercourse, pregnancy, contraception, STD, sexuality; responders score a point or more for each correct answer.	Administered using a semi-structured interview format that takes approximately 30 min; short and easy to administer, authors report "good internal consistency and split-half reliability"; no assessment of the test- retest reliability and usefulness for people with moderate or severe intellectual disabilities (Talbot & Langdon, 2006).

Questionnaire	Areas assessed	Reliability, validity, and evaluation
Bender Sexual Knowledge Questionnaire (1983)		
Sex-Ken (McCabe,1999)	Designed to evaluate the knowledge, experience, feelings, and needs of respondents; questions cover 13 different areas: friendship, dating and intimacy, marriage, body part identification, sex and sex education, menstruation, sexual interaction, contraception, pregnancy, abortion and childbirth, STD's, masturbation, homosexuality; has four parallel versions: SexKen- ID for people with mild intellectual disability, Sex-Ken-PD for people with physical disabilities, SexKen- C for caregivers of people with disabilities and SexKen designed for use in general population; allows to compare similarities and differences in the sexuality of different group of respondents, for example to contrast report of people with disabilities with	Very comprehensive (248 questions), which makes it very lengthy; reported by authors to have "good psychometric properties"; each aspect (knowledge, experience etc.) can be tested separately; no questions regarding high risk behaviours; can be completed as a questionnaire or interview; if done as a questionnaire it takes about 1 hour to complete; the version for people with intellectual disabilities structured in a such a way that it can be administered during three separate interviews, each one taking about 1 hour to complete; the subscales range from the least intrusive to the most; at the end of each interview there are knowledge questions to determine if respondents have sufficient knowledge to proceed to the next one; according

Questionnaire	Areas assessed	Reliability, validity, and evaluation
	answers given by their caregivers; the experience, feelings and needs items are either yes/no responses or are scored on a 5 point Likert type scale, the knowledge questions are open ended, with responses scored 0, 1 or 2; some items are categorical and do not contribute to the total score.	to the author, validity of the scale could not be assessed using another measure as no other scales existed at the time of development of SexKen (McCabe, 2010).
Sexual Knowledge Interview Schedule SKIS (Forchuk, 1981, as cited in Forchuk, Martin, Griffiths, 1995)	46 questions measuring sexual knowledge and experience; has an abuse scale and knowledge scale; items in the abuse scale generally ask about sexual experience; the knowledge scale consists of four subscales: feelings, body parts identification, body parts function and general sexual knowledge.	Format of interview reduces the required literacy; content validity established through opinion of clinical experts; used in a convenience sample of 37 adults with IQ = 70 or less; the inter- rater reliability 95.3% and test- retest 70.1%; the internal consistency (Cronbach's Alpha) for the abuse subscale was 0.96 and for knowledge was 0.90.

Questionnaire	Areas assessed	Reliability, validity, and evaluation
Sexual Vocabulary Test and Multiple Choice Questionnaire (Ousley, Mesibov, 1991)	Both instruments adapted from tests used in previous studies; 31 questions selected from the over 100 used by Wilcox and Udry in their 1986's study (as cited in Ousley, Mesibov, 1991); the Multiple Choice Questionnaire has two parts: sexual and dating experiences and interest in sexual activities.	Range of areas covered and questions limited, no psychometric evaluation of the measure (McCabe et al., 1999) except for inter- rater reliability, which was 0.98.
Socio- Sexual Knowledge and Attitudes Test (SSKAT) (Wish, Fiechtl, & Edmonson, 1977, as cited in Wish, McCombes & Edmonson, 1979)	Divided into 14 sections: anatomy terminology, menstruation, dating, marriage, intimacy, intercourse, pregnancy- childbearing, birth control, venereal disease, masturbation, homosexuality, alcohol and drugs, community risks and hazards, and terminology test; the original test consisted of 208 knowledge questions, 40 questions concerning attitudes, and 13 questions as to what extent the examinee thought that he or she knew about the subtest area; many of the questions are presented with	Test-retest reliability on knowledge items between 78 - 89%; validity assessed by 'experts' and rated as good (Watson, 2002); criticised for being time consuming, developed using institutionalised sample, outdated language rating attitudes, culturally specific to North America (Lambrick & Glaser, 2004), requiring a high level of skills to administer (Forchuk, Martin, & Griffiths, 1995), being overly complicated in parts, not exhaustive, not containing a detailed examination of sexual

Questionnaire	Areas assessed	Reliability, validity, and evaluation
	pictorial aids; the test was later revised by authors leaving it with 167 knowledge questions and 39 questions assessing attitudes.	activities in which responders might have engaged (McCabe, Cummins & Deeks, 1999).
Socio- Sexual Knowledge and Attitudes Tool Revised (SSKAAT-R) (Griffiths & Lunsky, 2003) updated version of the SSKAAT.	Revised version of the SSKAAT questionnaire; sections: anatomy; women's bodies: menstruation, menopause, cancer and more; men's bodies: privacy, masturbation, cancer and more; intimacy: dating, marriage, physical contact; pregnancy, childbirth & childrearing: where babies come from, baby care and adoption; birth control and STDs: methods and use of birth control, prevention/symptoms of STDs; healthy boundaries: appropriate and inappropriate touching and behaviours.	Described by authors as having "good psychometric properties"; can be used with those, whose language is limited, and with general population; comparison norms provided; age range 15-80 (Griffiths & Lunsky, 2003); pictures were updated; questions simplified, attitudes are not scored, test-retest 0.87-0.99 (Watson, 2002).