

The Sexual Health Knowledge of People with Intellectual Disabilities: a Review

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Published online: 9 November 2016
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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 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 Organization and 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 and McCabe 1995) but might also hold negative views towards sex (Bernert and Ogletree 2012). At the same time, many people with intellectual disabilities have sexual needs and hope to be in a relationship (Froese et al. 1999; Kelly et al. 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 and Neufeldt 2001; Rohleder and Swartz 2012), which may have many negative consequences, such as increased risk of sexually transmitted diseases (STD; Aderemi et al. 2013). What is more is that people with disabilities, especially children, are more vulnerable to abuse than their non-

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disabled peers (McKenzie and 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 and 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 et al. 2007; Timms and Goreczny 2002).

Despite the fact that more and more carers and professionals believe that sex education is needed (Lafferty et al. 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 et al. (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 et al. 2001). Some parents of adolescents with intellectual disabilities have been found to be resistant to discussing sex with their offspring (Pownall et al. 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 are also important for the purpose of counselling or therapy, as well as when investigating potential cases of sexual abuse (Bell and 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 amongst people with intellectual disabilities.

Method

This is a narrative review, and as such, it summarises 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 criteria 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 % 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 and Cameron 2003; Shapiro and 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 and 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 et al. 1999). In the majority of the studies, quantitative methods or mixed methods were used to collect data,

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

Authors, year and location	Sample	Method	Key results
Aderemi et al. (2013), Nigeria	300 participants (123 females), mean age = 16.3, with mild/moderate intellectual disabilities; 300 without disabilities (154 females), age range = 12–19	Structured questionnaire written by authors	Diagnosis of ID was significantly associated with lower HIV transmission knowledge (mean score = 52.85 compared to $M = 70.44$ for non-disabled students); level of knowledge about HIV transmission varied; male adolescents with ID were more knowledgeable than females with ID; learners with intellectual impairments had less access to sources of HIV information.
Bambury et al. (1999), New Zealand	18 adults (3 females), age range = 17–46, with mild intellectual disability	Socio-Sexual Knowledge and Attitudes Test, SSKAT (Wish et al. 1977, as cited in Edmonson et al. 1979)	Significant increases in knowledge of the students following educational programme.
Bender et al. (1983), UK	15 'hard-core' delinquents (mean age = 16) and 18 severely 'mentally handicapped' ^a young adults (mean age = 24); no exact information on range of IQ	Questionnaire developed by authors administered pre- and post-education	Adolescent boys more knowledgeable than 'mentally handicapped' adults; individuals in both groups ignorant regarding physiology and venereal disease; adults with mental handicap also presenting ignorance in the area of 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.
Caspar and 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, pretest $M = 9$ and posttest $M = 12.9$; all but one participants showed improvements.
Dawood et al. (2006), South Africa	90 adolescents (23 females), 14–6 years old, with mild 'mental retardation'	Questionnaire developed by authors	78 % of participants aware of STDs 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 (2012), USA	A convenience sample of 25 women (aged 24–59) with mild to moderate intellectual disabilities (IQ ranging from 55 to 75)	Pre- and post-training qualitative interview and audio computer-assisted self-interview	Except for one domain (identification of high-risk fluids), all participants showed significant gains in both HIV knowledge and condom application skills after training.
Dukes and McGuire (2006), Ireland	2 men and 2 females with a moderate intellectual disability, aged 22 and 23 years	The Sexual Consent and Education Assessment (Kennedy 1993, as cited in Dukes and McGuire 2006)	All participants improved their knowledge after education and, as a result, sexuality-related decision-making capacity; 6-month follow-up data for 3 of 4 individuals showed maintenance of scores on safety practices scores and some decay of knowledge scores.
Eastgate et al. (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

Table 1 (continued)

Authors, year and location	Sample	Method	Key results
			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.
Edmonson and Wish (1975), USA	18 moderately 'retarded' males, aged 18–30 years; 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 et al. (1979), USA	99 institutionalised adults (50 females), aged 18–42, IQs from 27 to 74; 100 adults living in community (50 females), aged 18–42, IQs from 23 to 70	SSKAT (Wish et al. 1977, as cited in Edmonson et al. 1979)	Good knowledge about anatomy, dating, marriage, intercourse (69–70 % of correct answers); the responders were least knowledgeable about birth control, venereal disease and homosexuality.
Fischer and Krajicek (1974), USA	16 moderately 'retarded' adolescents (8 females); aged 10–17 years, 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; 81–94 % correct answers for identifying pictures of hugging, kissing and intercourse; meagre knowledge of pregnancy.
Forchuk et al. (1984), Canada	42 'mentally retarded' participants with behavioural and/or psychiatric problems staying in hospital, maximum IQ = 68, aged 16–65 years	Verbal test administered pre- and post-education	About half of the participants knew one method of contraception compared to over 70 % after the course; 11 people could give accurate answer on what sex or sexual intercourse means before the training compared to over half of the participants after.
Galea et al. (2004), Australia	96 adults with mild (75 % of the sample) and moderate intellectual disability (42 females), mean age = 31.5	Questionnaire: Assessment of Sexual Knowledge (ASK) developed by authors	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, menopause, sexuality, safer sex practices, sexual health, STD, sexual rights and contraception; no gender differences in knowledge (except for menstruation).
Garwood and McCabe (2000), Australia	6 men with mild intellectual disabilities who took part in training	Sexual Knowledge, Experiences and Needs Scale, Sex-Ken (McCabe 1999)	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 posttest.
Gillies and McEwen (1981), UK	79 'mildly subnormal' students from special schools and 475 pupils from ordinary secondary schools; aged 14 and 16 years	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 on contraception; no age differences; majority of 'mildly subnormal' participants had good comprehension of sexual intercourse.

Table 1 (continued)

Authors, year and location	Sample	Method	Key results
Hall et al. (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 and Morris (1976), USA	61 institutionalised young people (30 females), mean age = 17.3, mean IQ = 63.6; 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 et al. (2009), Ireland	32 participants (12 females); aged 13–31; 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, STDs 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.
Isler et al. (2009), Turkey	60 students with mild and moderate intellectual disabilities; aged 15–20 years	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 et al. (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 STDs; 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.
Konstantareas et al. (1997), Canada	31 individuals aged 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 and Mihokovic (2007), Croatia	24 adults (10 females), aged 19–53; 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

Table 1 (continued)

Authors, year and location	Sample	Method	Key results
Lindsay et al. (1992), UK	2 groups with mild or moderate intellectual disabilities; group 1: 46 adults (mean age = 28.7) who participated in sex education; group 2: 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	of situational forms; low levels of knowledge in the area of STDs and methods of protection; overall level of knowledge was insufficient. The mean number of correct answers for masturbation, puberty, intercourse, pregnancy and childbirth was around 30–40 %; only 20 % for birth control and <5 % for venereal disease; the group receiving sex education improved their knowledge significantly; improvements maintained to a 3-month follow-up.
Lockhart et al. (2010), Ireland	3 groups of 8 people each (7 males) with mild and moderate intellectual disabilities: (1) group with sexualised challenging behaviour; (2) group with non-sexualised challenging behaviour; and (3) group of individuals with no challenging behaviour; age range = 25–65 years	The Socio-Sexual Knowledge and Attitudes Assessment Tool Revised (SSKAT-R) (Griffiths and Lunsky 2003, as cited in Lunsky et al. 2007)	All participants showed good knowledge of body part 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 in all groups; no significant group effect was observed for sexual knowledge.
Long et al. (2013), 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 et al. (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); borderline IQ (19 %) to mild (61 %), moderate (16 %) and severe (4 %)	SSKAT-R (Griffiths and Lunsky 2003, as cited in Lunsky et al. 2007)	Participants with offence 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 those individuals who had received prior sex education were compared, there were no differences in knowledge between groups.
McCabe and 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, as cited in McCabe and Cummins 1996)	People with ID demonstrated lower levels of knowledge than participants from the 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 1999)	People with ID presented lower levels of sexual knowledge and experience, more negative attitudes to sex and stronger sexual needs than people with physical disabilities, who in turn had lower levels of knowledge compared to people from the general population; participants with ID had

Table 1 (continued)

Authors, year and location	Sample	Method	Key results
McDermott et al. (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)	poor knowledge about contraception, STD, sexual interaction and menstruation; 30 % correct answers for pregnancy/childbirth and masturbation. 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; 60 undergraduate students (25 females), aged 13–31	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 et al. (2006), UK	Cohort 1: 17 male sex offenders (mean IQ = 66, mean age = 34) and 20 males with no history of inappropriate sexual 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)	SSKAT (Wish et al. 1977, as cited in Edmonson et al. 1979)	Sex offenders had the same or greater level of knowledge than the control group; highly significant correlation between IQ and sexual knowledge for non-offenders and no significant correlation for sex offenders.
Murphy et al. (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 and Morris (1993), USA	32 participants (16 females), aged 21–65; 20 individuals had mild 'mental retardation', 6 moderate, 5 severe and 1 borderline; 26 people also had diagnosis of psychiatric condition	SSKAT (Wish et al. 1977, as cited in Edmonson et al. 1979); capability assessed by professionals	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 %.
O'Callaghan and Murphy (2007), UK	60 adults with ID, aged 21–62 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 and if they were allowed to marry); young people without ID were more knowledgeable.
Ousley and Mesibov (1991), USA	21 people with high functioning autism (10 females), mean IQ = 79.15, mean age = 27 years; 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.
Penny and Chataway (1982), Australia	44 participants with mild and 5 with moderate 'retardation' (21 females), mean age = 22 years	Especially constructed sex vocabulary test administered pre- and post-education	Women scored lower, but the difference did not reach significance; all participants showed increases in knowledge between pretest and

Table 1 (continued)

Authors, year and location	Sample	Method	Key results
Robinson (1984), Australia	83 participants, IQ between 50 and 80, aged 16–52; 41 participants attended sex education programme; remaining participants acted as a control	SSKAT (Wish et al. 1977, as cited in Edmonson et al. 1979)	posttest following an educational intervention. No difference in knowledge between sexes; community-based individuals more knowledgeable than those institutionalised before the sex education; all experimental participants showed improvement in knowledge.
Ruble and Dairymples (1993), USA	Survey of 100 parents of individuals with autism, 84 % of people within 'mental retardation' range, age range = 9–38 years	Sexuality Awareness Survey developed using a sample of 10 parents	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.
Siebelink et al. (2006), The Netherlands	76 participants (29 females); 56 with mild, 4 moderate and 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 and McCabe (1995), Australia	25 participants (15 females), mean age = 25.2, with mild intellectual disabilities; control group of 39 students (29 females), mean age = 22.5	Sex-Ken (McCabe 1999)	Highest scores amongst people with ID for body part identification; least knowledge about STDs 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.
Timmers et al. (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 and Lee (1999), Hong Kong	77 females (aged 11–15 years) with mild 'mental retardation'	Personal Safety Questionnaire and the 'What if' Situation Test (Wurtele 1990, as cited in Tang and Lee 1999)	Participants possessed limited information about sexual abuse; sexual knowledge was the best predictor of ability to mobilise self-protection skills.
Talbot and Langdon (2006), UK	4 groups of participants: (1) sex offenders with ID who did engage in treatment ($n = 12$, mean IQ = 64.9); (2) sex offenders with ID and no history of treatment ($n = 13$, mean IQ = 62.4); (3) non-offenders with ID ($n = 28$); (4) non-offenders without ID ($n = 10$)	Updated version of Bender Sexual Knowledge Questionnaire (Bender et al. 1983)	Participants without ID scored significantly higher than people with ID; sex offenders with ID who had undergone treatment scored higher than those who had not received treatment; assumption that lower sexual knowledge may be related to the risk of committing a sexual offence has not been proven.
Watson and 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 the control group; students from special school had some basic knowledge.

ID intellectual disabilities

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

with the exception of Eastgate et al. (2011), Healy et al. (2009) and Kelly et al. (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 (nine in the UK, four in Ireland and one each in Croatia, Turkey, the Netherlands and Poland), 13 in the USA, 9 in Australia, 3 in Canada and 1 each in Nigeria, South Africa, Hong Kong and New Zealand.

Sample sizes vary from 4 (Dukes and McGuire 2006) 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 et al. 1999; Brantlinger 1985; Dawood et al. 2006; Fischer and Krajicek 1974; Gillies and McEwen 1981; Hall et al. 1973; Isler et al. 2009; Tang and Lee 1999; Watson and Rogers 1980) or institutions (such as residential settings and hospitals; Edmonson et al. 1979; Caspar and Glidden 2001; Forchuk et al. 1984; Hall and Morris 1976; Long et al. 2013; Niederbuhl and Morris 1993; Penny and Chataway 1982; Siebelink et al. 2006) or from offender populations (Lockhart et al. 2010; Lunskey et al. 2007; Michie et al. 2006; Murphy et al. 2007; Talbot and Langdon 2006). Only five studies recruited people living in the community (Garwood and McCabe 2000; McCabe 1999; McCabe and Cummins 1996; Szollos and McCabe 1995; Timmers et al. 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's 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 (1975) study, the level of knowledge varied from 10 to 65 % correct responses to a questionnaire, and in the research of Aderemi et al. (2013) 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 STDs 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 whether there was a link between the level of functioning and the level of knowledge, but no generalisable conclusions can be made. This somehow surprising result might be due to factors such as lack of uniform terminology, use of poor quality assessment tools, scantiness or inadequacy of description of the samples used and/or results, and 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 the 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 et al. 1992; Lockhart et al. 2010; Szollos and McCabe 1995; Timmers et al. 1981), whilst others found low levels of knowledge in these areas (Bender et al. 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 age. In the Isler et al. (2009) study, participants were asked about internal organs such as tubes, ovary and 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, whilst Bender et al. (1983), Isler et al. (2009), Jahoda and Pownall (2014) Kelly et al. (2009), McCabe (1999) and Szollos and McCabe (1995) obtained contrary results. There

are no differences in the methods and samples used in the studies that could explain these dissimilar results. It is also not clear from the papers whether the topic of ‘sexual intercourse’ refers to general sexual activity between two people or whether 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 and Morris 1976; Leutar and Mihokovic 2007; Timmers et al. 1981) and others that the level is low (Bender et al. 1983; Fischer and Krajicek 1974; Kijak 2013; Lindsay et al. 1992; McCabe 1999). No differences in the 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 (1975), 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), Fischer and Krajicek (1974), Garwood and McCabe (2000), Healy et al. (2009), Isler et al. (2009) and 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 regard to knowledge about menstruation. Some authors found that the level of information was low (Galea et al. 2004; Garwood and 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) found 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 the 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 and Mihokovic 2007),

participants showed good recognition of public/private spaces; in two, sound knowledge of socially appropriate/inappropriate behaviour (Leutar and 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 STDs appears to be the most lacking (Bender et al. 1983; Edmonson et al. 1979; Galea et al. 2004; Gillies and McEwen 1981; Hall and Morris 1976; Kijak 2013; Leutar and 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 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 the study of Timmers et al. (1981), 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 STDs, 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 2012; McGillivray 1999) showed deficits in knowledge, especially about transmission and cure of HIV/AIDS. However, Delaine (2012) 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, the 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 and Wish 1975; Hall et al. 1973; Konstantareas et al. 1997; Leutar and Mihokovic 2007; Michie et al. 2006; O’Callaghan and Murphy 2007; Ousley and 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 and 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 Edmonson and Wish (1975), there was no correlation between years of institutional residence and correct responses.

Many authors (e.g. Lindsay et al. 1992; Penny and 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 real-life situations (O’Callaghan and Murphy 2007). However, research conducted by Delaine (2012), Dukes and McGuire (2006), McDermott et al. (1999), Murphy et al. (2007) and Robinson (1984) show that increases in knowledge were observed after taking part in training and on follow-up (posttests 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 posttest completed shortly after completion of sex education and posttest 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 et al. 1997; Leutar and Mihokovic 2007; McGillivray 1999; Ousley and Mesibov 1991; Siebelink 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 and Pownall 2014; Penny and Chataway 1982), and in one paper, women had higher levels of knowledge than men (Szollos and 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 regard 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 and Mesibov 1991; Konstantareas et al. 1997). No studies were found regarding other diagnoses.

Factors related to limited knowledge might be problems with communication and limited reading ability (Tang and 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 (2014) research, 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 is that 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 and Morris 1976; Tang and Lee 1999; Turk and Brown 1993) and may increase risk of having STDs (Aderemi et al. 2013; McGillivray 1999) and unplanned pregnancies (Cheng and 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 intellectual disabilities (Barron et al. 2002). However, Talbot and Langdon (2006), Lunskey 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 than 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 (2006) 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 the use of 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 and 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 preexisting 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 and Glidden 2001; Delaine 2012; Dukes and McGuire 2006; Eastgate et al. 2011; Garwood and McCabe 2000; Kelly et al. 2009; Leutar and Mihokovic 2007; Murphy et al. 2007; Szollos and 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 a 'pen and paper' method, which could lead to non-generalisable 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 and Glidden 2001; Hall et al. 1973; Isler et al.

2009; Penny and Chataway 1982; Timmers et al. 1981). Other measurements that had the reliability and validity assessed, and sometimes were used in more than one project, are listed and evaluated in Table 2. The authors of this review relied on information regarding the 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 to not 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, 2010) contains 248 questions, taking an hour to complete as a questionnaire and up to 3 h if completed as an interview. Siebelink et al. (2006) suggest that the assessment should take no longer than 30 min. 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 et al. 1990; Heiman et al. 1998). Galea et al. (2004) suggest that, since research on sexuality contains sensitive material, it can be difficult to recruit participants. Some authors (Hellemans et al. 2007; Ruble and Dalrymple 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 and 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 decisions 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,

Table 2 Review of tools measuring sexual health knowledge

Questionnaire	Areas assessed	Reliability, validity and evaluation
Assessment of Sexual Knowledge (ASK; Galea et al. 2004)	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-item 'yes' or 'no' response; the knowledge section divided into 15 topics: parts of the body, public and private, puberty, menstruation, menopause, masturbation, relationships, protective behaviours, sexuality, safer sex practices, contraception, pregnancy and birth, and sexual health—screening tests, STD, 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 consists of questions of how a person feels about a particular subject.	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 the 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 Knowledge Quiz is a predictor of knowledge scores in the ASK, but is recommended rather as an initial screening tool and not to replace a comprehensive assessment (Galea et al. 2004).
General Sexual Knowledge Questionnaire (GSKQ; Talbot and Langdon 2006)—revised and updated version of Bender Sexual Knowledge Questionnaire (1983)	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

Table 2 (continued)

Questionnaire	Areas assessed	Reliability, validity and evaluation
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, masturbation and homosexuality; has four parallel versions: Sex-Ken-ID for people with mild intellectual disability, Sex-Ken-PD for people with physical disabilities, Sex-Ken-C for caregivers of people with disabilities and Sex-Ken designed for use in the general population; allows to compare similarities and differences in the sexuality of different groups of respondents, for example to contrast report of people with disabilities with 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.	reliability and usefulness for people with moderate or severe intellectual disabilities (Talbot and Langdon 2006). Very comprehensive (248 questions), which makes it very lengthy; reported by author 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 h to complete; the version for people with intellectual disabilities structured in such a way that it can be administered during three separate interviews, each one taking about 1 h to complete; the subscales range from the least intrusive to the most; at the end of each interview, there are knowledge questions to determine whether respondents have sufficient knowledge to proceed to the next one; according 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 Sex-Ken (McCabe 2010).
Sexual Knowledge Interview	46 questions measuring sexual knowledge and	Format of interview reduces the

Table 2 (continued)

Questionnaire	Areas assessed	Reliability, validity and evaluation
Schedule, SKIS (Forchuk 1981, as cited in Forchuk et al. 1995)	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.	required literacy; content validity established through opinion of clinical experts; used in a convenience sample of 37 adults with IQ = 70 or less; inter-rater reliability of 95.3 % and test–retest of 70.1 %; the internal consistency (Cronbach's alpha) for the abuse subscale was 0.96 and for knowledge was 0.90.
Sexual Vocabulary Test and Multiple Choice Questionnaire (Ousley and 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 study (as cited in Ousley and 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 et al. 1977, as cited in Edmonson et al. 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 pictorial aids; the test was later revised	Test–retest reliability on knowledge items between 78 and 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 and Glaser 2004), requiring a high level of skills to administer (Forchuk et al. 1995), being overly complicated in parts, not

Table 2 (continued)

Questionnaire	Areas assessed	Reliability, validity and evaluation
	by authors, leaving it with 167 knowledge questions and 39 questions assessing attitudes.	exhaustive, not containing a detailed examination of sexual activities in which responders might have engaged (McCabe et al. 1999).
Socio-Sexual Knowledge and Attitudes Tool Revised (SSKAT-R; Griffiths and Lunsky 2003, as cited in Lunsky et al. 2007), 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 and 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 the general population; comparison norms provided; age range, 15–80 (Lunsky et al. 2007); pictures were updated; questions simplified, attitudes are not scored; test–retest, 0.87–0.99 (Watson 2002).

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 overrepresented.

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 life span, including children, adolescents, adults and older adults. More research is needed in places such as Africa, Asia and South America, as currently most of the available research has been done in Europe, North America and Australasia. Given the risk of HIV amongst 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 communicating 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 most effective when information is repeated several times, and this points to a collaborative approach between various stakeholders to ensure education takes place in 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 the study characteristics and study results, but we chose to concentrate primarily in reviewing the 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 STDs the least.

The assessment of knowledge is important so that the most appropriate and relevant materials can be included in sex education programmes. 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

Funding This study had no funding.

Ethical Approval This article does not contain any studies with human participants or animals performed by any of the authors.

Conflict of Interest The authors declare that they have no conflicts of interest.

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