ANGLIA RUSKIN UNIVERSITY

FACULTY OF SCIENCE AND ENGINEERING

AN EXAMINATION OF THE SEXUAL HEALTH KNOWLEDGE, EXPERIENCES, AND NEEDS OF PEOPLE WITH LEARNING DISABILITIES

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ABSTRACT

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The primary aim of the research was to investigate the sexual health and relationships knowledge of people with learning disabilities (LD). This was to clarify the details of knowledge held, and to identify gaps and misunderstandings, which could be translated into practical implications helping to design better educational and personal support.

The project is divided into three studies. Study 1 concentrated on assessment of the sexual health knowledge, experiences and needs of people with LD. Interviews with 27 people with LD were conducted. The data was analysed in two ways: quantitative summaries of answers to the questionnaire measuring sexual health knowledge, and qualitative analysis, which focused on incorrect answers and misunderstandings. Study 2 was an on-line survey for parents of people with LD. Caregivers (n = 83) were asked about their perceptions of the sexual health knowledge of their children. Study 3 was conducted using semi- structured interviews with teachers (n = 15) involved in delivery of sex education to people with LD. The data was analysed using Framework Analysis.

The results of my studies show that the knowledge concerning sexual health and relationships of people with LD is highly variable, from very simplistic to full awareness of issues related to sex and relationships. Sexual and relational experiences of people with LD are varied. The sex-related parent-child communication was shown to be related to the perceived sexual health knowledge of children with LD as assessed by parents. Parental neuroticism was associated with the level of perceived knowledge of the children. Teachers and educators who took part in the Study 3 talked about general difficulties when working with people with LD, but also about challenges specific to the subject. They shared their tips, advice and good practice.

Based on the results of the studies, many practical recommendations regarding sex education, interviewing people with LD, support for parents and teachers are presented.

Key words: sexual health knowledge, sex education, learning disability, sexuality, SEN.

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Abbreviations

AAIDD	American Association on Intellectual and Developmental Disabilities
APA	American Psychiatric Association
ASD	Autistic Spectrum Disorder
BPS	British Psychological Society
DfE	Department for Education
DoH	Department of Health
DSM	Diagnostic and Statistical Manual of Mental Disorders
ICD	International Statistical Classification of Diseases and Related Health Problems
LD	Learning Disability/ies
OFSTED	Office for Standards in Education
PLK	Perceived level of knowledge
PSHE	Personal, Social and Health Education
SEN	Special Educational Needs
Sex-Ken	Sexual knowledge, experiences and needs questionnaire
SRE	Sex and relationships education
STD / STI	Sexually transmitted diseases/ infections
WHO	World Health Organisation

1. Chapter One

General Overview

There is a growing recognition that people with learning disabilities (LD) 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 sexual health of people diagnosed with LD.

Available research shows that adults with LD, on average, not only present lower levels of knowledge on sexual health 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 LD have sexual needs and hope to be in a relationship (Froese, Richardson, Romer, & Swank, 1999; Kelly, Crowley, & Hamilton, 2009). Research shows that many individuals with LD, especially with mild impairments, are sexually active (McCabe, 1999; McGillivray, 1999). However, sex education is not always available as concluded by Milligan and Neufeldt (2001), who reviewed literature regarding sexuality of people with disabilities. Currently, in England pupils in all schools, including special schools, are taught about relationships and sexual health through sex and relationship education (SRE) and personal, social, health and economic education (PSHE) lessons (Department for Education- DfE, 2017). However, the provision of the SRE is not compulsory at the primary level and not always adequate in secondary schools (OFSTED, 2002). Lack of education or inappropriate provision of it may have many negative consequences, such as increased risk of sexually transmitted diseases (STDs) (Aderemi, Pillay, & Esterhuizen, 2013). Mandell et al. (2008) found that, in a sample of 51,234 adolescents ages 12–17 from the USA, those receiving special education services (8015) were at a greater risk of being diagnosed with an STD. Specifically, they identified that girls with

LD were 37% more likely to contract an STD than were girls without LD. It is unclear whether those in special education included in the sample were receiving sex education.

Statistically, people with LD are up to four times more likely to be victims of sexual abuse than the rest of the population (Mencap, Respond & Voice UK, 2001). However, 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 LD, especially women, as uncovered by interviews with service providers in South Africa (Meer & Combrinck, 2015). According to Meer and Combrinck (2015), service providers' narratives indicated that the experiences of women with LD, including their vulnerability to and experiences of violence were mediated by multiple complex social perceptions and myths. These included the general view that people with disabilities are less valuable, cultural myths and superstitions about disability, fear and shame associated with "disabled" sexuality, beliefs about the lack of credibility of persons with LD, and the tendency of persons with disabilities to internalise negative views about themselves. Finally, some authors suggested 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, McConkey, & Simpson, 2012), many of them experience anxiety and ambivalence towards 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 in South Africa recognised a number of challenges in their work, including cultural values and expectations, learners' knowledge and behaviour, handling of sexual abuse cases and the teachers' professional preparation. Not only educators, but also support staff working with people with LD reported being inadequately trained in the area of the sexual health (Christian, Stinson, & Dotson, 2001). Some parents of adolescents with LD in Scotland have been found to be resistant to discussing sex with their offspring (Pownall & Jahoda, 2012).

As a precursor to identifying gaps in sex education and responding to specified concerns by the UN (2006) and WHO (2006, 2011), information is needed about the knowledge people with LD have about sex. The nature and extent of support required can best be determined through a careful assessment of the 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) wrote that education was the key to empower individuals to identify, report and prevent sexual assault and abuse.

The primary aim of the research forming the basis for this thesis was to investigate the sexual health and relationships knowledge of people with LD. The research also investigated views and concerns of parents, and experiences of teachers involved in the delivery of sex education to people with LD. The research questions were as follows:

1. What is the level of knowledge about relationships and sex among people with LD?

2. What sexual needs and experiences do they have?

4. What do parents believe their children with LDs know and understand about sex and relationships (perceived level of knowledge – PLK)?

5. What affects parental views regarding sex education and knowledge of their children with LD?

6. What are teachers and educators' experiences of delivering sex and relationships education to people with LD?

The project is divided into three studies. Study 1 involved people with LD. Participants' sexual health knowledge, sexual experiences and needs were investigated. Study 2 focused on the parents of people with LD. Parental perception of their children's sexual knowledge was explored as well as their views regarding sex education of people with LD. Finally, Study 3, concentrated on the views and experiences of teachers involved in the delivery of sex and relationship education to learners with LD.

To orient the reader, the structure of the thesis will be briefly outlined. Chapter Two provides background information regarding sexual health knowledge, sexual experiences, and needs of people with LD. In addition, literature regarding views of parents of people with LD

regarding sex-related education and communication is reviewed. Finally, information related to views and experiences of teachers involved in delivery of sex and relationships education (SRE) is summarised.

Chapter Three details the first study. Study 1 concentrated on assessment of the sexual health knowledge, experiences and needs of people with LD. This chapter summarises the results of interviews conducted with 27 people with LD using questions from the Sex-Ken- ID questionnaire. The data was analysed in two ways: quantitative summaries of answers to the questionnaire, and qualitative analysis, which focused on incorrect answers and misunderstandings, presented by the participants. In addition, a critique of the Sex-Ken tool and the scoring manual is presented, accompanied by recommendations.

Chapter Four provides details of Study 2. Study 2 was an on-line survey for parents of people with LD. Caregivers were asked for their perceptions of the sexual health knowledge of their children. Participants (n = 83) were also asked to complete a number of additional measures (sociodemographic questionnaire, tools assessing personality, stress and locus of control) in order to identify factors associated with the perception of knowledge and views on sex education.

Chapter Five describes Study 3. Study 3 was conducted using semi- structured interviews with teachers and educators involved in delivery of SRE to people with LD. The data was analysed using Framework Analysis. The findings consist of three main themes identified, with emphasis on practical recommendations.

Finally, Chapter Six delineates the key findings and practical implications of the thesis. The limitations are discussed, as well as recommendations for further research.

1.1 Evolution of the Project

Initially, my research was going to be concentrating on the experiences of young people with LD and the views of their parents. I was planning to compare what adolescents with LD knew about sexual health and relationships and what their carers thought they knew. This was going to be tested using parallel versions of the SexKen questionnaire: SexKen- ID designed to be used with people with LD and testing sexual health knowledge, experiences and needs, and SexKen- C, which consists of the same questions as SexKen-ID, but asks for carers' perception

of the knowledge, experiences, and needs of people with LD. I was hoping to recruit parent-child pairs and ask both – an adolescent with LD and their parent/s to complete the appropriate questionnaires. SexKen-ID is intended to be completed in the form of an interview, whilst the version for parents is a pen and paper questionnaire. In addition to comparing the young persons' knowledge with their parents' perception, I was going to investigate factors that might have an effect on parental perception of the children's knowledge. Moreover, I was going to see if there were any differences between people with different types of diagnosis. To do that, I was planning to recruit young people (13 – 20 years old) diagnosed with Autistic Spectrum Disorder, Down's syndrome and mild LD (30 participants for each group). What is more, a subgroup of parents was going to be interviewed, using a semi-structured interview schedule aimed at investigating their views and concerns regarding the sexual development of their children and their views on sex education. The data was going to be collected over two or three meetings. During the first two meetings parents were going to be asked to complete SexKen- C, a personality test (Big- 5) and a sociodemographic questionnaire, whilst I was interviewing their children in a separate room using SexKen- ID. The third meeting was going to be optional for parents willing to take part in in-depth interviews.

Over a period of 12 months, approximately 30 organisations were contacted in order to recruit participants, including Mencap, who disseminated information about my research to all of their branches in the East of England region (for full details see Chapter 3.3.1.1). However, I only interviewed two young people with LD and one parent (not related to the interviewed young persons). Due to the sensitive nature of the topic of my research, I was expecting that recruitment would be the biggest challenge of my project. The fact that potential young participants required permissions from their parents/carers was one of the reasons why the recruitment was so difficult. The main concern expressed by the parents of potential participants was that the participation in a project regarding sexuality might lead to increased usage or interest in sexualised words or behaviour. One mother, who contacted me, did not want her daughter to be involved in my research because she was a victim of sexual abuse; therefore, she was concerned that participation in my project might bring unwanted memories back. Another mother, who considered giving permission for her daughter to be interviewed by me insisted that she was present in the same room during the interview. Her presence was not requested due to any particular concerns, for example about her daughter's or mine's safety, or to assist with

communication. As a result, I informed her that it would not be possible for her to be in the same room because of confidentiality; however, she could be nearby, for example in the room next door. She did not wish to go ahead with such an arrangement.

To improve recruitment, I made some changes to the project. I increased the age of the young people to 25 years. As no parent-child pair agreed to take part in the research, the idea was no longer pursued. The adaptations did not make any difference to the recruitment. Therefore, finally, the upper age limit regarding potential participants with LD was removed, so that potential adult participants could give consent themselves. A monetary incentive was offered to the participants with LD, who agreed to take part in the study (£10). The project was divided into three stand-alone studies. Study 1 measured sexual health knowledge, experiences and needs of people with LD. The second study was changed to an on-line study exploring the views of parents regarding the sexual health knowledge of their children (perceived level of knowledge – PLK) and what factors were related to this. What is more, a study exploring views and experiences of teachers delivering sex education to people with LD was added (Study 3). Even though they are three separate studies, all assess the sexual health knowledge of people with LD, but from different perspectives: people with LD themselves, parents of people with LD and the teachers' point of view.

1.2 Contribution to Knowledge

A published literature review regarding the level of knowledge of people with LD about sexual health conducted by myself, found that in the past 50 years 48 articles were published on the topic (Borawska-Charko, Rohleder, & Finlay, 2016). However, in only 31 of them the assessment of the knowledge was the main aim of the research and the general sexual health knowledge and not specific areas of it, for example regarding the law or AIDS, was investigated. Five of the previous studies concerned people with LD who were sex offenders (Lockhart, Guerin, Shanahan, & Coyle, 2010; Michie, Lindsay, Martin, & Grieve, 2006; Murphy, Powell, Guzman, & Hays, 2007; Lunsky, Frijters, Griffiths, Watson, & Williston, 2007; Talbot & Langdon, 2006) and three those had dual diagnosis of LD and mental health problems (Forchuk, Pitkeathly, Cook, Allen, & McDonald, 1984; Long, Krawczyk, & Kenworthy, 2011; Niederbuhl & Morris, 1993). Only 11 studies were carried out in the UK. Most importantly, the majority of the results were not consistent and sometimes even contradictory, for example, when it comes to

the relationship between the level of knowledge and IQ and the best and least known areas (see Chapter 2.1.1). Hence, it is still an area that requires further investigation.

In addition, what makes my research unique is the fact that the topic of sexual health knowledge of people with LD was examined from the point of view of all concerned: the people with disabilities themselves, the parents and the sexual health educators. What is more, I used mixed methods of data collection and analysis, which gave me the opportunity to investigate the subject in depth. I hope that my research will lead to better educational programs and interventions for people with LD and support for parents and teachers, and as a result- increase the knowledge and safety of people with LD.

1.3 Definitions

I use the term "learning disabilities" (LD) in the thesis, which is commonly utilised in the UK. The latest "Guidance on the Assessment and Diagnosis of Intellectual Disabilities in Adulthood" published by the Faculty for People with Intellectual Disabilities of the Division of Clinical Psychology at the British Psychological Society (BPS, 2015) as well as the Diagnostic and Statistical Manual of Mental Disorders (DSM-5) published by the American Psychiatric Association (APA, 2013), employ the term "intellectual disability". However, as the term "learning disabilities" is still being used by the National Health Service (NHS), UK Government, Mencap and other leading organisations in the field, as well as by the service users and professionals, the decision was made to use it. Across the world and organisations, different terms are utilised, including: "disorders of intellectual development" used in the International Statistical Classification of Diseases and Related Health Problems (ICD-11; WHO, 2018), and "developmental delay" or "developmental disabilities" in the USA as a broad, umbrella term to refer to intellectual disabilities and pervasive developmental disorders (Davey, 2008).

Learning disability is defined by the BPS (2015) as significant impairment in intellectual functioning and significant impairment in adaptive behaviour (social functioning), with each of these impairments beginning prior to adulthood. It has been accepted generally that a "significant impairment of intellectual functioning" is best represented by an IQ score below 70. This is the criterion recommended by all three major international classification systems currently (DSM-5, APA, 2013; ICD-11, WHO, 2018; and American Association on Intellectual and Developmental Disabilities (AAIDD-11), 2010). It is also the benchmark recommended by the British

Psychological Society (2015). When it comes to adaptive functioning, according to the DSM- 5 (APA, 2013), LD involves impairments of general mental abilities that affect adaptive functioning in three domains: conceptual, social and practical. These domains determine how well an individual copes with everyday tasks:

- The conceptual domain includes skills in language, reading, writing, math, reasoning, knowledge, and memory.
- The social domain refers to empathy, social judgment, interpersonal communication skills, the ability to make and retain friendships, and similar capacities.
- The practical domain centres on self-management in areas such as personal care, job responsibilities, money management, recreation, and organizing school and work tasks (APA, 2013).

Deficits in intellectual functioning and adaptive behaviour are established by using psychometrically valid standardised assessment tools used in combination with other relevant and complementary clinical evaluations and information (e.g., review of records, qualitative interviews etc.). There are four levels of LD: mild (IQ 50-70), moderate (IQ 35-49), severe (IQ 20-34) and profound (IQ below 20) (APA, 2013). However, both DSM-5 (APA, 2013) and the BPS guidelines (2015) emphasize the role of adaptive functioning over IQ scores. Public Health England (2016) estimated that in 2015, 1,087,100 people in England had LD, of which 930,400 were adults (aged 18+). The latter is equivalent to 2.16% of the English adult population.

The WHO (2006) defines sexual health as "a state of physical, emotional, mental and social well-being in relation to sexuality" (p.5). Sexuality, in turn, is a broad term, which has varied over time, and it lacks a precise definition. In common usage, the term refers to sexual orientation. The WHO provides the following definition of sexuality: "a central aspect of being human throughout life encompasses sex, gender identities and roles, sexual orientation, eroticism, pleasure, intimacy and reproduction. Sexuality is experienced and expressed in thoughts, fantasies, desires, beliefs, attitudes, values, behaviours, practices, roles and relationships" (p.5, WHO, 2006). The Merriam-Webster dictionary defines sexuality as: **"**the quality or state of being sexual: the condition of having sex, sexual activity, expression of sexual

receptivity or interest especially when excessive (Merriam-Webster, 2019). As the definition of "sexuality" is broad and unclear, mainly, the term "sexual health" will be used in this thesis.

2. Chapter Two

Literature Review

This chapter will offer an overview of what is known about the sexual health knowledge, the sexual experiences and the needs of people with LD, as well as reviewing the literature that has investigated the views and concerns of the parents and teachers. As knowledge is the main focus of the thesis, the most attention is paid to it.

2.1 Sexual Health Knowledge of People with Learning Disabilities

Summary of published papers regarding sexual health knowledge of people with LD presented in this section was based on the review article written by myself (Borawska – Charko et al., 2016). The original search was conducted using a number of electronic databases (PubMed, EBSCOhost, Science Direct, and Google Scholar). 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 inclusion criteria applied were: published papers, written in English and presenting original research specifically about LD and not disabilities in general. Included articles had to present data on the level of knowledge about sexual health knowledge and relationships in general or specific aspects of it, e.g. sexual abuse or sexually transmitted diseases. The original search was conducted between June 2013 and January 2014. Hence, another search was done to check if any articles were published since then. One additional paper was found (Pownall, Wilson, & Jahoda, 2017). The published review included studies assessing sexual health knowledge of people with ASD, which was not a part of the literature review for this thesis. Therefore, one paper was removed (Hellemans, Colson, Verbraeken, Vermeiren, & Deboutte, 2007), however the two articles which compared people with autism and LD were included, leaving a total of 48 articles.

In previous research, the 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 the 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-one 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 LD (e.g. US Department of Health and Human Services, 2000; UK Department of Health, 2001). With regard to locality, 19 articles reported research carried out in Europe (11 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 varied from four (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 (e.g. Aderemi et al., 2013), institutions (such as residential settings and hospitals) (e.g. Caspar & Glidden, 2001), or from offender populations (e.g. Lockhart et al., 2010). Five studies recruited people living in the community (Garwood & McCabe, 2000; McCabe, 1999; McCabe & Cummins, 1996; Szollos & McCabe, 1995; Timmers, DuCharme, & Jacob, 1981). When it comes to the levels of disability of the participants, 32 articles reported using mixed or unspecified samples, 12 with mild, and four moderate LD.

In general, previous studies found that sexual knowledge amongst people with LD was often lacking in certain areas, was inaccurate, or contained misconceptions. A key finding of the literature review is that no obvious differences were observed between studies across the five decades in terms of overall knowledge, which appears to be consistently low. There has also been little change in terms of the 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. However, there were considerable individual differences and variability in the level of knowledge. 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.'s (2013) research about HIV awareness, the level of knowledge about HIV transmission varied from 0 to 100% correct answers.

In order to make comparisons and draw conclusions regarding the knowledge of specific groups of people with LD, different ways of organising the papers were considered. Grouping the articles according to the level of LD of participants was looked at. Unfortunately, this was not possible as most of the papers (32 out of 48) reported on data from mixed or unspecified samples. Another criterion considered was the age of the participants. I attempted to organise the papers into groups with participants aged up to 20 years old, 20-40 and 40-60+, but most articles included samples with broad age ranges, therefore this was not possible. Finally, the articles were divided into two groups- young participants- up to 20 years old (13 papers, Table 1) and adults 20+ years old (30 papers, Table 2). The division is not ideal as many articles relate to heterogeneous groups (for example aged 9- 36, Ruble & Dalrymple, 1993). In such a situation, mean age was the criterion for inclusion. In addition, two of the papers did not specify the age of the participants. Healy et al. (2009) reported that 32 participants who took part in their focus groups were allocated into three age groups (13-17 years,18-30 years, 31+ years), but they do not specify how many people were in each group nor the mean age. Therefore, a decision was made to include this paper in both tables and report information relevant to each of the age groups. Paper by Long, Krawczyk and Kenworthy (2011) does not include any information about the age of the participants. What is more, the participants were women in a secure psychiatric facility with dual diagnosis of LD and mental illness and personality disorder. This potentially means that the sexual health knowledge is not representative to whole population of people with LD. Hence, the article was not included in further analysis.

A separate review of articles including offenders (5 in total) is presented in Table 3. All papers are presented in a chronological order.

Table 1

Papers regarding sexual health knowledge of young people with LD

Authors and location	Sample	Method	Key Results
Hall, Morris, Barker (1973) USA	56 "mentally retarded[1]" participants and 5 with LD (30 females); mean IQ= 66.6; mean age= 17.7 (10 – 24 years old).	A 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.
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.
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.	An 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.
Watson, Rogers (1980) UK	194 mildly "educationally subnormal students" (96 female), mean age= 14.5; 61 children from a 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 the special school had some basic knowledge.

[1]I used 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.

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.	The "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 the "mildly subnormal" participants had good comprehension of sexual intercourse.
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.
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.
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; erroneous beliefs regarding transmission of HIV and the cure for HIV.
Isler, Tas, Beytut, Conk (2009) Turkey	60 students with mild and moderate LD; 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.
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.
Aderemi, Pillay,	300 participants (123 females), mean age=16.3, with mild/moderate LD;	Structured questionnaire.	Diagnosis of LD was significantly associated with lower HIV transmission knowledge (mean score = 52.85 comparing to

Esterhuizen (2013) Nigeria	and 300 without disabilities (154 females), mean age=15.4. age range 12 to 19 yrs.		M=70.44 for non-disabled students); level of knowledge about HIV transmission varied; male adolescent with LD were more knowledgeable than females with LD; learners with LD had less access to sources of HIV information.
Jahoda, Pownall (2014) UK	30 adolescents with mild LD (14 females) and 30 non- disabled adolescents (15 females), all participants aged 16-21 years old.	Structured interview with questions drawn from the Sex-Ken (McCabe, 1999), SSKAT (Wish et al., 1977) and the ASK (Galea et al., 2004).	Adolescents without disabilities scored significantly higher than those with LD; women with LD had lower levels of knowledge than men with LD.
Pownall, Wilson, Jahoda (2017) UK	29 participants with LD (15 females), mean age= 18.5, mean IQ= 59.4; 31 participants with no disability (17 females), mean age= 18.7, mean IQ= 97.1; and 23 participants with physical disabilities (PD) (7 females), mean age= 16.7, mean IQ= 95.7.	Health knowledge questionnaire developed by the authors.	Comparison of knowledge regarding healthy eating, alcohol and pregnancy and contraception between the groups; participants without any disabilities scored significantly higher on information regarding pregnancy and contraception than the others groups; no difference in knowledge between participants with LD and physical disability.

Table 2

Papers regarding sexual health knowledge of adults with LD (aged 20+)

Authors and location	Sample	Method	Key Results
Edmonson, Wish (1975) USA	18 moderately "retarded" males, aged 18-30 years old; IQs from 30 to 55.	A 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.	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.
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.
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 the difference did not reach significance; all participants showed increases in knowledge between pre-test and post- test of knowledge following educational intervention.
Bender, Aitman, Biggs, Haug (1983) UK	15 "hard-core" delinquents (mean age= 16) and 18 severely "mentally handicapped" 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 group ignorant regarding physiology and venereal disease; adults with "mental handicap" also presenting ignorance in the area of contraception; the "handicapped" group showed increased sexual knowledge after a human relations course; no relation between age and knowledge.
Forchuk, Pitkeathly, Cook, Allen,	42 "mentally retarded" participants with behavioural and/or psychiatric problems staying in hospital;	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

McDonald (1984) Canada	maximum IQ= 68; aged 16 to 65 years.		accurate answers on what sex or sexual intercourse means before the training, comparing to over half of the participants after.
Robinson (1984) Australia	83 participants, IQ between 50 and 80, aged 16 to 52; 41 study participants attended sex education program, remaining participants acted as a control.	The pre and post-test was the SSKAT (Wish, et al. 1977).	No difference in knowledge between the sexes; community-based individuals more knowledgeable than institutionalised before the sex education; all experimental participants showed improvement in knowledge.
Ousley, Mesibov (1991) USA	21 people with high functioning autism (10 females); mean IQ = 79.15, mean age= 27 years; and 20 people with LD (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 LD.
Lindsay, Bellshaw, Culross, Staines, Michie (1992) UK	2 groups with mild or moderate LD; 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.
Ruble, Dalrymple (1993) USA	Survey of 100 parents of individuals with autism, 84% of people within "mental retardation" range; age range 9 to 38 years old.	The 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.
Niederbuhl, Morris (1993) USA	32 participants (16 females); aged 21 to 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); capability assessed by professional team.	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%.

Szollos, McCabe (1995) Australia	25 participants (15 females); mean age=25.2 with mild LD; control group of 39 students (29 female), mean age=22.5.	Sex-Ken (McCabe, 1993) completed in a form of individual interviews.	Highest scores amongst people with LD for body part identification; least knowledge about STDs and sexual interaction; overall low levels of knowledge; the students showed greater knowledge than people with LD in all but two areas: body part identification and dating and intimacy.
McCabe, Cummings (1996) Australia	30 participants (18 females) with mild LD, mean age=25.2; control group of 50 students (32 females), mean age=20.6.	Sex-Ken questionnaire (McCabe, 1993).	People with LD demonstrated lower levels of knowledge than participants from control group on all subscales, except for body part identification and menstruation where there was no difference between groups.
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 about 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.
McCabe (1999) Australia	60 people with mild LD (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 LD 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 LD had poor knowledge about contraception; STDs; sexual interaction; menstruation; 30% correct answers for pregnancy/childbirth and masturbation.
McGillivray (1999) Australia	60 adults (25 females), aged 18-59 years, with mild/moderate LD; and 60 undergraduate students (25 females), aged 13 to 31.	An assessment instrument developed by author based on existing measures.	Participants with LD 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.
McDermot, Martin, Weinrich, Kelly (1999)	252 women (average age 31.9 years) with mild "mental retardation"; mean IQ score= 59.9.	Knowledge assessed using Social Sexual Assessment (author unkown).	Statistically significant positive change over 1 year for sexual knowledge; hygiene, social interactions and sexual experience affected sexual knowledge.

USA			
Bambury, Wilton, Boyd (1999)	18 adults (3 females), age range 17-46 years old with mild LD.	SSKAT (Wish, et al. 1977).	Significant increases in knowledge of the students following educational program.
New Zealand			
Garwood, McCabe (2000)	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.
Australia			
Caspar, Glidden (2001)	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 participant showed improvements.
USA			
Galea, Butler, Iacono, Leighton (2004)	96 adults with mild (75% of the sample) and moderate LD (42 females), mean age=31.5.	ASK (Galea, et al., 2004).	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, STIs, sexual rights, and contraception; no gender differences in knowledge (except for menstruation).
Australia			
Siebelink, de Jong, Taal, Roelvink (2006)	76 participants (29 females); 56 with mild, 4 moderate, 11 borderline LD (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.
The Netherlands			
O'Callaghan. Murphy (2007)	60 adults with LD, aged 21 to 62 years, mean IQ= 59.8; 60 young	Questionnaire developed by authors to assess	Adults with LDs 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 LDs (e.g.

UK	people aged 16- 18 years without disabilities	understanding of sex and the law.	whether they could have sexual relationships, if they were allowed to marry); young people without LD's were more knowledgeable.
Leutar, Mihokovic (2007) Croatia	24 adults (10 females), aged 19 to 53; 18 participants with mild LD and 6 with moderate; participants were recruited from members of summer camp.	Questionnaire created by authors administered in a form of interview.	Good knowledge of differences between genders and pregnancy; relatively good knowledge in distinguishing between appropriate and inappropriate 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.
Dukes, McGuire (2009) Ireland	2 men and 2 females with a moderate LD 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 months follow- up data for 3 of 4 individuals showed maintenance of scores on safety practices' scores and some decay of knowledge scores.
Healy, McGuire, Evans, Carley (2009) Ireland	32 participants (12 females); aged 13 to 31+; severity of disability not specified.	Focus group interviews.	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.
Kelly, Crowley, Hamilton (2009) Ireland	15 participants (7 females), ranging in age from 23 to 41 years; no data on level of LD.	Focus group interviews.	Sexual knowledge was limited; three individuals who had received formal sex education were able to display an understanding of sexual intercourse, procreation, contraception and STIs, the remaining participants (three quarters of the sample) had limited level of knowledge.
Eastgate, Van Driel, Lennox, Sheermeyer (2011) Australia	9 women with mild LD; 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.

Kijak (2013) Poland	133 participants (42 females) with "higher degree" of LD, aged 18-25.	Structured interviews.	89% of participants had very good knowledge about their own sexes' 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.
Delaine (2013) USA	A convenience sample of 25 women (age 24 to 59) with mild to moderate LD (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.

Table 3

Papers regarding sexual health knowledge of sexual offenders with LD

Authors and location	Sample	Method	Key Results
Talbot, Langdon (2006) UK	4 groups: 1) sex offenders with LD, who did engage in treatment (n=12; mean IQ = 64.9), 2) sex offenders with LD and no history of treatment (n=13; mean IQ=62.4), 3) non-offenders with LD (n=28), 4) non-offenders without LD (n=10).	Updated version of Bender Sexual Knowledge Questionnaire (Bender et al., 1983).	Participants without LD scored significantly higher than people with LD; sex offenders with LD 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.
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 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).	The sex offenders had 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; no correlation between age of participants and knowledge.
Murphy, Powell, Guzman, Hays (2007) UK	8 men with LD (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.
Lunsky, Frijters, Griffiths, Watson, Williston (2007)	48 men with LD with sexual offence history and 48 men with LD 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%).	The SSKAT-R (Griffiths & Lunsky, 2003).	Participants with history of offense 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

Canada			individuals who had received prior sex education were compared, there were no differences in knowledge between groups.
Lockhart, Guerin, Shanahan, Coyle (2010) Ireland	3 groups of 8 people in each (7 males, 1 female) with mild and moderate LD: (1) group of people 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 old.	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.

2.1.1 Sexual health knowledge of young people with LD.

What is remarkable about the papers relating to sexual health knowledge of young people with LD is the fact that most of the articles were published prior to 2000 (Hall et al., 1973; Fischer & Krajicek, 1974; Hall & Morris, 1976; Watson & Roger, 1980; Gillies & McEwen, 1981; Brantlinger, 1985; Tang & Lee, 1999). In fact, six out of 13 studies involving adolescents were conducted during the 1970's and 1980's. This could be related with "availability" of participants. In the past, many of the adults with LD lived in institutions. Access to individuals with LD in those establishments was potentially more difficult compared to young people attending schools.

Another interesting fact is that nearly half of the studies (6) were comparisons between students with and without LD (Hall & Morris, 1976; Watson & Roger, 1980; Gillies & McEwen, 1981; Aderemi et al., 2013; Jahoda & Pownall, 2014; Pownall et al., 2017). All the papers concluded that adolescents without disabilities presented better knowledge regarding sexuality than those with diagnosis of LD.

There is no consensus when it comes to the best and least known topics. In three of the studies, authors observed that the knowledge of sexual intercourse was good (Fischer & Krajicek, 1974; Hall & Morris, 1976; Gillies & McEwen, 1981) whilst Isler et al. (2009) noted that participants knew little about it. This is surprising as the studies, where knowledge of sexual intercourse was found to be good, were conducted approximately 40 years ago, whilst the Isler et al.'s study is fairly recent. One would expect that the knowledge of sexual intercourse increased with time, considering that nowadays exposure to sexual activities presented in the media is much more common. The observation cannot be explained by the level of LD as the participants in all studies had mild and moderate LD. Perhaps, the results are associated with location. Studies where the knowledge was found to be good were conducted in the USA and UK, whereas Isler et al.'s (2009) study was in Turkey. A large majority of Turkish people are Muslims (99%, European Commission, 2019) and the country is considered to be very conservative. In Islam, men and women are required to dress modestly and adultery is regarded as a very serious crime (British Broadcasting Company, n.d.). People with LD, especially young

ones, potentially are not exposed to sexual activities such as kissing, whether presented in media or in public spaces, and as a result their knowledge might be poorer.

Knowledge of STDs appears to be poor among young people with LD (Hall et al., 1973; Hall & Morris, 1976; Gillies & McEwen, 1981). Dawood et al. (2006) reported that the majority of their participants were aware of STDs and HIV, but the knowledge regarding transmission was erroneous. Another topic where the knowledge is meagre is contraception (Hall et al., 1973; Hall & Morris, 1976; Gillies & McEwen, 1981). Masturbation (Fischer & Krajicek, 1974; Isler et al., 2009) and menstruation (Gillies & McEwen, 1981; Isler et al., 2009) are also not well known, except for participants in Hall and Morris's (1976) study who were knowledgeable about masturbation and menstruation.

When it comes to relationships between the age of the participants and the level of knowledge, the results are not consistent. Hall et al. (1973) reported that knowledge increased with the chronological and mental age, whilst Gillies and McEwen (1981) observed no difference. However, this finding can be explained by the range of ages of participants who took part in the studies. In Hall et al.'s (1973) study, the age of participants ranged from 10 to 24 years old, whereas in Gillies and McEwen's (1981) study the age gap was much smaller (14-16 years old). Potentially the age gap in the latter study was not big enough to observe any difference, especially if the participants varied in their level of functioning, which could mean that their mental age was similar.

2.1.2 Sexual health knowledge of adults (20+) with LD.

Overall, 30 papers formed this part of the review (article by Healy et al., 2009 was included in both reviews- regarding adolescents and adults). Ten of the studies (Penny & Chataway, 982; Forchuk et al., 1984; Robinson, 1984; Lindsay et al., 1992; McDermott et al., 1999; Bambury et al., 1999; Garwood & McCabe, 2000; Caspar & Glidden, 2001; Dukes & McGuire, 2009; Delaine, 2013) tested effectiveness of training on the level of knowledge. All concluded that sex education improved the knowledge of the participants, apart from knowledge of masturbation and menstruation in the Garwood and McCabe's (2000) study.

When it comes to factors affecting the level of knowledge, there is no consensus. Ousley and Mesibov (1991) reported that there was a positive correlation between the IQ of the

participants and their knowledge, whereas McDermott et al. (1999) observed no difference between the individuals with mild and moderate LD. Similarly, Ousley and Mesibov (1991) noted lack of correlation between the knowledge and sexual experiences, whilst McDermott et al. (1999) stated that sexual experiences affected the knowledge.

Siebelink et al. (2006) found no difference in knowledge between different age groups. No other papers reported on relationship between age and the level of knowledge. Four of the papers (Robinson, 1984; Konstantareas & Lunsky, 1997; Galea et al., 2004; Siebelink et al., 2006) observed no gender differences when it came to the knowledge of participants. Penny and Chataway (1982) noted that women in their study scored less, but the result did not reach statistical significance.

Knowledge of STDs appears to be lacking the most. Seven of the papers reported that it was the least known topic to their participants (Edmonson et al., 1979; Bender at al., 1983; Lindsay et al., 1992; Szollos & McCabe, 1995; McCabe, 1999; Galea et al., 2004; Leutar & Mihokovic, 2007). It was noted in six of the articles, that the knowledge of contraception was poor (Edmonson et al., 1979; Bender et al., 1983; Lindsay et al., 1992; McCabe, 1999; Galea et al., 2004; Kijak, 2013). However, Timmers et al. (1981) and Healy et al. (2009) found that adults with LD in their samples were knowledgeable about it. Poor knowledge of masturbation, pregnancy, menstruation and childbirth was observed in three studies each.

When it comes to topics that are well known to people with LD, it was reported in five of the papers that the participants held good knowledge of body parts (Edmonson et al., 1979; Timmers et al., 1981; Szollos & McCabe, 1995; Galea et al., 2004; Kijak, 2013). Pregnancy was mentioned as a well-known topic in four of the articles (Timmers et al., 1981; Konstantareas & Lunsky, 1997; Galea et al., 2004; Leutar & Mihokovic, 2007).

2.1.3 Sexual health knowledge of sexual offenders with LD.

The paper by Lockhart, Guerin, Shanahan and Coyle (2010) included in this review did not concern offenders but individuals with sexualised challenging behaviour. However, as the study was testing a hypothesis that sexualised, challenging behaviour of adults with LD is associated with low levels of sexual knowledge, similarly to other papers (e.g. Talbot & Langdon, 2006), a decision was made to include it.

Four out of the five articles involving offenders included in this review compared sexual health knowledge of people with LD with and without history of sexualised offensive/ challenging behaviour. Michie et al. (2006) found that offenders with LD had higher levels of knowledge than those with LD with no history of offending. Lunsky et al. (2007) reported that offenders with LD who engaged in sexually inappropriate behaviour (i.e. public masturbation) did not differ in terms of sexual knowledge from their matched sample of individuals with LD with no sexual offence history, whereas offenders who had committed more serious offences (i.e. paedophilia) demonstrated greater sexual knowledge than matched non- offenders. Talbot and Langdon (2006) and Lockhart et al. (2010) concluded that there were no group differences in knowledge between offenders with LD and individuals with LD not displaying any sexualised challenging behaviour. However, in the study by Lockhart et al. (2010), when they controlled for adaptive behaviour, the knowledge of individuals displaying sexualised challenging behaviour was better than those who did not display such a behaviour.

In the study by Talbot and Langdon (2006), those offenders who had undergone treatment scored significantly higher than non-offenders with LD on some section of the sexual knowledge questionnaire. The increase in sexual health knowledge amongst offenders with LD who took part in treatment was also reported by Murphy et al. (2007).

Correlation between level of functioning and the knowledge was mentioned in two of the papers. Talbot and Langdon (2006) observed strong correlation between IQ and scores on sexuality questionnaire. Michie et al. (2006) also noted such a relationship but only for non-offenders with LD.

2.1.4 Knowledge by areas.

Body parts and physical characteristics. Some studies reported 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 & McCabe, 1995; Timmers et al., 1981) while others found low levels of knowledge in these areas (Bender et al., 1983; Healy et al., 2009; Isler et al., 2009).

***Sexual intercourse*.** It is not clear from the papers if the topic of "sexual intercourse" referred to general sexual activity between two people, or if it was specific to heterosexual

penetrative sex. Only McGillivray (1999) explained that the term "sexual activity" in her research referred to oral- genital sex or vaginal/anal 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 (2014) Kelly et al. (2009), McCabe (1999) and Szollos and McCabe (1995) obtained contrary results.

Pregnancy. There is no agreement about the level of knowledge about pregnancy, with some research showing that individuals with LD 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).

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.

Menstruation. Inconsistent results were also achieved with 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.

Legal aspects. Two studies investigated knowledge about legal aspects pertaining to sex and relationships. O'Callaghan and Murphy's study (2007) only investigated knowledge regarding illegal behaviours, for example sex with a minor or between people with LD and professionals. Questions in Galea et al.'s study (2004) were divided into two types: those regarding the rights of people with LD concerning sexual interactions and relationships and illegal behaviours. O'Callaghan and Murphy (2007) found that adults with LD presented very limited understanding of the law, lower than control group consisting of younger participants, but with no LD. Galea et al. (2004) found that knowledge of illegal behaviour was good, but insufficient for the rights of people with disabilities.

Social norms. Social norms can be defined as knowledge regarding public/private and socially appropriate behaviour, for example masturbation in public. 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 the reasons why some behaviour was inappropriate.

Contraception and sexually transmitted diseases. Knowledge regarding contraception and STDs appears to be the most lacking. Authors of all studies which examined this aspect of sexual health, described the knowledge as being poor (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.'s (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 several 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 LD regarding HIV/AIDS (Aderemi et al., 2013; Dawood et al., 2006; Delaine, 2013; McGillivray, 1999) showed deficits in knowledge, especially about the transmission and cure of HIV/AIDS. However, Delaine (2013) demonstrated that knowledge could be improved by training.

Contradictory and inconsistent results achieved in previous studies might be due to many factors. The main reason is that people with LD 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 LD should be labelled. Some papers did not report the means or ranges of IQ of the participants (e.g. Kelly et al., 2009) or only referred to the level of disability, for example "severely mentally handicapped" (Bender et al., 1983). It is also unclear in some of the studies how the severity of the disability was assessed. Some studies, therefore, might report on a mixed group of people, some of whom may not fall into the definition of having "learning disabilities."

In addition, in the majority of the studies (29), authors have used questionnaires developed by them for the purpose of the study with little or no attention paid to psychometric properties (more information can be found in Chapter 3.3.2). The tools vary in terms of how comprehensive and detailed they are, for example, the questionnaire used by Siebelink et al. (2006) only had four knowledge questions, compared to 98 knowledge questions in the SexKen (McCabe, 1999). Most of the researchers administered their questionnaires in the form of an 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 higher functioning were included. What is more, in most cases, I relied on the authors' assessments of whether the knowledge of the participants was good or poor as reported by them in the results sections of the papers. This could be very subjective and there is no standardised way of judging it as none of the available questionnaires have norms.

Another factor that could contribute to the fact that the results were inconsistent was that different areas of the sexual health were defined differently. For example, in some of the studies, the topic of body parts was only regarding external body parts (e.g. McCabe, 1999). In Isler et al.'s (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 knowledge of internal body parts might be poorer. In other areas, for example, sexual interactions/intercourse, it is unclear how the terms were defined and what activities were included.

2.1.5 Factors related to sexual knowledge.

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, as some authors point out (e.g. Talbot & Langdon, 2006), it is not clear how much the better performance of people with milder impairments in any assessments is due to better communication or reading skills and how much to greater knowledge levels. 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.

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 suggested that the effects of receiving sex education might 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), and Robinson (1984) demonstrated 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 suggested that it might be due to informal learning occurring by sharing of information amongst participants who formed friendships during the sex education course.

Gender does not seem to be associated with the level of knowledge (Galea et al., 2004; Konstantareas & Lunsky, 1997; Leutar & Mihokovic, 2007; McGillivray, 1999; Ousley & Mesibov, 1991; Robinson, 1984; Siebielink et al., 2006). Only four articles showed gender differences. In three studies, men with LD were found to be more knowledgeable than women (Aderemi et al., 2013; Jahoda & Pownall, 2014, 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 LD 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 studies that involved offenders with LD did not show a difference in knowledge (Lunsky et al., 2007; Talbot & Langdon, 2006). Additionally, Ousley and Mesibov (1991) found no correlation between experience and the level of knowledge amongst people with "developmental delay" and autism.

With 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 LD and found no difference (Ousley & Mesibov, 1991; Konstantareas & Lunsky, 1997). No studies were found regarding other diagnoses, such as Prader-Willi.

Another factor, which might be related to lower levels of knowledge, is 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 LD generally have much smaller social networks. For example, in Jahoda and Pownall's research (2014) disabled young people reported less formal and informal sources of sexual information and described smaller social networks than their non-disabled peers. Pownall et al. (2017) compared the health knowledge of young people without disabilities, those with LD and those with physical disabilities in Scotland. They found that participants with disabilities (physical and LD) were less knowledgeable about pregnancy/ contraception than young people without, which suggests that deficits in sexual knowledge were not just result of cognitive deficits, but that social exclusion could play a role as well. What is more, individuals with LD have a much more restricted access to the types of leisure activities where people would exchange information pertaining to sexuality. Nowadays, the digital exclusion of some people with LD may also play a role in their limited knowledge.

2.1.6 Consequences of limited knowledge.

There are many possible consequences of low levels of sexual knowledge amongst people with LD. It is suggested that inadequate and incomplete knowledge might be contributing to the fact that people with LD are at greater risk of abuse (Hall & Morris, 1976; Tang & Lee, 1999;

Turk & Brown, 1993) and may increase the risk of having STDs (Aderemi et al., 2013, McGillivray, 1999) and unplanned pregnancies (Cheng & Udry, 2005). Shapiro and Sheridan (1985) implied that limited knowledge of reproductive health care may lead to the higher occurrence of undetected cancer amongst women with LD. 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 LD (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 presented the same or even higher levels of knowledge than people with no known history of sex offending. Timms and Goreczny (2002) and teachers working with people with LD interviewed by Garbutt et al. (2010) suggested that the 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.

2.1.7 General methodological issues.

There are many general difficulties in assessing sexual knowledge in this population. A major problem is that most tools designed to evaluate knowledge, have not been tested for their psychometric properties (see Thompson, Stancliffe, Wilson, & Broom, 2016). The phrasing of certain questions may be too difficult for people with LD 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 SexKen scale (McCabe et al., 1999; McCabe, 1999; McCabe, 2010) contains 244 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 LD may experience

problems with memory and recalling information. Furthermore, all 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) suggested that since research on sexuality contains sensitive material, it could be difficult to recruit participants. Some authors (Helleman et al., 2007; Ruble & Dairymple, 1993) chose to base their research on the estimation of proxies (e.g. parents) instead of individuals with LD or autism. One main concern is that people with disabilities 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 for young people with LD, who took part in sex- related research and no increase in sexual behaviour or talk as reported by the tutors of the participants. In fact, the tutors reported that several students appeared to have been positively affected by their participation.

In England, in the case where participants are below 16 or if they are found to be incapable of making the decisions for 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 sex is not a taboo topic, and who might therefore achieve higher scores on sex- related knowledge measures, might be over-represented.

The aim of Study 1 forming this thesis was to assess the sexual health and relationships knowledge of people with LD to further clarify the details of knowledge held, and to identify gaps and misunderstandings which could be translated into practical implications helping to design better educational and personal support.

2.2 Sexual and Relational Experiences of People with Learning Disabilities

People with LD share a human need for affection and intimate relationships. A review of qualitative studies investigating people with LD's views on relationships (Whittle & Butler, 2018) uncovered that the majority of papers reported that people with LD had a desire to be involved in an intimate relationship and expressed a wish for future marriage. However, they

might have difficulty in establishing and maintaining such relationships due to a lack of knowledge how to do so and a lack of social and practical support. The document published by the England's government *Valuing People* (2001) recognised that need and sought to develop opportunities for people with LD "to form relationships, including ones of a physical and sexual nature" (p.81). However, the *Valuing People Now* (2009) report highlighted a lack of progress. The importance of relationships is now incorporated into British law as part of the Care Act (2014). The development and maintenance of personal relationships is considered an eligible need, which means that local authorities must at a minimum meet needs at this level (Bates, Terry, & Popple, 2017).

There is little current research into how many people with LD are in a relationship. Research conducted with 2,898 people with LD who were at least 16 years old and lived in England found that most of the people (92%) were single and had always been single, some were married or were living with someone (6%), and 2% were widowed, separated or divorced (Emerson, Malam, Davies, & Spencer, 2005). In comparison, the 2011 census reported that 49% of adults in England were married (Office for National Statistics, 2011). This data did not include how many people were in informal relationships.

When it comes to sexual experiences, McGillivray (1999) interviewed 60 adults with mild/moderate LD in Australia. Eighteen percent of participants in the sample reported current sexual activity, but the total was 60% when those with previous experiences were included. McCabe and Cummins (1996) found that 80% of the respondents with mild LD in their sample had experience of kissing and 48% of sexual intercourse. In the study by Siebelink et al. (2006), 76% of participants with mild to moderate LD had experiences of kissing and hugging and 45% of sexual intercourse. The numbers appear to be much lower for adolescents with LD. Dekker, Safi, Echteld and Evenhuis (2014) interviewed young people (15-18 years) with mild LD in the Netherlands. Of the 28 participants, 68% had been in a relationship and 18% had experience of sexual intercourse (Dekker et al., 2014). Cheng and Undry (2005) found that out of 422 young people with "low cognitive abilities" in the USA (mean age = 16.7), 63% of boys and 82% of girls had never had sex.

The lack of experience can be due to many reasons. Shakespeare, Gillespie-Sells and Davies (1996) in their book list a number of barriers that disabled people face when it comes to being sexual:

1. Socialization
2. Segregation
3. Sex education
4. Physical barriers
5. Residential institutions
6. Personal assistance
7. Internalised oppression

People with LD often experience isolation and lack opportunities for socialisation and as a result, they miss out not only on discussions about sex, which could lead to informal learning, but also on potential opportunities to form relationships and gain sexual experiences. The segregation starts in infancy and continues into adulthood. Children attend special schools and even if they go to afternoon clubs or events, these are usually organised by the schools, so they miss many opportunities for meeting new people. The situation is even worse for individuals who are in residential settings, which are usually controlled environments. Many people with LD have negative experiences of attending organised events as they feel they are patronised and over- controlled (Shakespeare et al., 1996). People with LD often have to rely on the help of others to get to places and even if they overcome this difficulty, not all the facilities are accessible for them. These experiences also strengthen their view of themselves as being different and that sex, parties and socialisation are not for them. Another difficulty is that disabled people, especially those with physical impairments, are never on their own. They are accompanied by teachers or TAs at school, family members or personal assistants at home or staff if they live in a supported accommodation (Shakespeare et al., 1996).

The aim of Study 1 forming this thesis was to investigate experiences related to relationships and sexual interactions of people with LD.

2.3 Sexual and Relational Needs of People with Learning Disabilities

Few studies have investigated sexual and relational needs. Siebelink et al. (2006) interviewed 76 adults with mild to moderate LD in the Netherlands. Male responders reported more sexual needs than did females. Ninety-one percent of males who took part in the study expressed need for kissing, compared to 76% of females, 67% of males wanted to have sexual intercourse (70% of females) and 70% reported the need to masturbate (36% of females). The same percentage of males and females (85%) expressed the need to hug. When it comes to having a partner, 88% of females and 89% of males wanted to have a girlfriend/ boyfriend. The authors did not notice a difference in the needs across different age groups in the sample.

Kelly et al. (2009) ran focus groups with 15 people with LD (level of disability not specified) in Ireland. Desire to be involved in an intimate relationship emerged as a strong theme in the data. Healy et al. (2009) who also ran focus groups with 32 people with LD in Ireland (no details about severity) reported that all participants in their sample expressed an interest in having relationships and friendships with members of the same and opposite sex.

Konstantareas and Lunsky (1997) compared sexual knowledge, experiences and needs of people with LD and autism. Relational needs did not vary as a function of group membership (LD vs. ASD), gender, or cognitive ability. Most participants (no exact numbers given) reported an interest in marrying and having children, but fewer (no details provided) expressed an interest in sexual activities.

2.4 Views of Parents of People with Learning Disabilities

There is an agreement that parents are their children's first and most important educators (Turnbull, van Wersch, & van Schaaik, 2008). Half of young people without disabilities (aged 11 – 14), who took part in a survey conducted by the Sex Education Forum (a charity advocating for quality sex and relationships education (SRE)), said that they wanted to talk to their parents about sex as they considered information obtained from them as more reliable and correct compared to their peers (Sex Education Forum, 2011). The role of parents as educators when it comes to sex and relationships was also recognised and recommended by the Department for Education (DfE, 2000). The SRE guidance published by the DfE (2000) emphasised the role of parents as they are seen as able not only to educate their children about sex- related topics, but

also to compliment the knowledge with faith and cultural values. Many parents see the need of equipping their children with knowledge necessary to stay safe and healthy. However, they also report having a lack of information and support in relation to this area (Garbutt, 2008). What is more, a literature review conducted by Turnbull et al. (2008) showed that in the majority of studies, parents of children without disabilities reported feelings of embarrassment and discomfort when discussing sex with their children.

Sex education presents numerous dilemmas for any parent, but for the parent of a young person with LD there may be additional challenges. Parents may be uncertain about how much their child can understand and how having a specific disability affects their child's sexuality. Families are often torn between promoting normalisation and dealing with matters of sexuality. One of the concerns is that by discussing matters of relationships and intimacy, they might raise false hopes and expectations (Shakespeare et al., 1996). However, Pownall, Jahoda and Hastings (2012) found that mothers of children with LD and without were similarly confident in dealing with their children's developing sexuality. To address these concerns, it has been proposed that schools should educate parents, as this would lead to a more comprehensive system of teaching SRE (Turnbull et al., 2008).

Effective communication within families plays a vital role when it comes to education about sexual matters (Turnbull et al., 2008). Results of previous research showed that parental communication with children without disabilities is related to later sexual initiation, a smaller number of sexual partners and better contraceptive use (DiIorio, Pluhar, & Belcher, 2003; Fisher, 1986a; Ogle, Glasier, & Riley, 2008; Turnbull et al., 2008). However, two studies, which examined the impact of communication on sexual knowledge of children (without disabilities), rather than behaviours, did not find an association between communication and knowledge. Mueller and Powers (1990) found that participants, who perceived their parents as friendly, relaxed, attentive, precise, dramatic, and good communicators during sexual conversations reported lower sexual information accuracy, which was an unexpected result. Fisher (1986b) found no difference in sexual knowledge of adolescents without disabilities between those who came from "high communication" families compared to those from "low communication." When it comes to factors having an impact on quantity and quality of within family sex- related

discussion, variables such as gender, were investigated. More details about these can be found in Chapter 4.1.1.

Parental impact on the sexuality, in a broad meaning of this term, of their children is not only limited to the transmission of sexual health information, but also affects attitudes and behaviours. Following a review of studies, Whittle and Butler (2018) concluded that it would appear that caregivers' beliefs about sexuality of people with LD could act to either inhibit or facilitate positive expressions of sexuality. Lofgren- Martenson (2004), after analysis of qualitative data, also observed that what individuals with LD believed about sex and relationships seemed to be strongly influenced by the attitudes and values of their parents and staff.

As this chapter has highlighted, parents play an important role in the sexual development of their children, not only as educators, but also by influencing attitudes and beliefs. Previous studies mainly concentrated on experiences of families of non-disabled children, but it can be speculated that parents of children with LD play an even more important role in the lives of their children. Therefore, Study 2 regarding parental perceptions of their children's knowledge, not only investigated what parents think that their children know about sexual health, but also explored parental views on the sex education of their children and factors that might be related to parental communication about sexual health issues.

2.5 Provision of Sex and Relationship Education and Experiences of Teachers

Currently, the law in England requires that primary schools can decide whether SRE should be included in their school's curriculum, whilst secondary schools must provide SRE (including information about HIV/ AIDS and other STIs) and must teach human growth and reproduction. Parents have the right to withdraw their children from all or part of any SRE, with the exception of the biological aspects of human growth and reproduction forming part of the science National Curriculum (Durex et al., 2010). However, from September 2020, the Department for Education is introducing compulsory Relationships Education for primary pupils, and Relationships and Sex Education (RSE) for secondary pupils. In addition, from September 2020 it will be compulsory for all schools to teach Health Education. This includes special schools as well. Parents will have a right to withdraw their child from sex education delivered as part of SRE in secondary schools. There will be no right to withdraw from the relationships'

aspects of the education at primary or secondary level as the contents of these subjects – such as family, friendship, safety (including online safety) is considered important for all children to be taught (DfE, 2019).

This is a welcome change, which is hoped to entail better preparation for teachers and improved resources (Cowles, 2018). In the survey conducted by Durex et al. (2010) amongst mainstream school leaders (people responsible for Personal, Social and Health Education - PSHE) and governors in the UK, 80% and 79% respectively reported that teachers did not feel confident and trained in talking about SRE, and as a result, almost quarter (23%) of all the participants believed that the current provision of SRE did not prepare children well enough. Other difficulties mentioned by teachers involved in the delivery of SRE in the mainstream schools in England, apart from lack of training and resources, included the fact that the subject was often delivered by staff who did not choose to do it (frequently form tutors) and did not necessarily feel comfortable and enthusiastic about it. Lack of support from the senior management team, and lack of time for preparation and delivery of SRE were also listed (Strange, Forrest, Oakley, Stephenson & the RIPPLE Study Team, 2006). In another study, conducted in the public schools in the USA, 31- 41% teachers (depending on which grade they taught) reported difficulty teaching certain topics (abortion, homosexuality, birth control and how to use condoms) due to actual or potential pressures from the school administration, parents or the community (Landry, Singh, & Darroch, 2000).

There is a paucity of research investigating views and experiences of sex education teachers and educators working with adolescents and adults with LD. Study 3, forming part of this thesis, addresses the gap. It aimed to investigate views and experiences of teachers and educators involved in the delivery of sex education to people with LD. In addition, teachers' perception of their students' sexual health knowledge was explored.

Overall, as shown in this chapter, the topics of sexual health knowledge and sexual experiences of people with LD require further examination. Despite the fact that there were many attempts to assess the knowledge of individuals with LD, the results are inconsistent and need further clarification. To my knowledge, only one previous study investigated parental perception of child's knowledge. Ruble and Dalrymple (1993) asked parents of individuals with

autism (84% had LD) to complete a survey that addressed the social sexual awareness, sex education, and sex behaviours. The study was conducted in the United States over 25 years ago. Views of parents and teachers concerning sexual health knowledge of people with LD are important pieces of the puzzle that can help form a full picture of the gaps, difficulties and misunderstandings. This information, in turn, could be used to form better educational programmes, interventions and support plans for people with LD. The following chapters will outline results and findings from three studies: Study 1, which focused on the assessment of sexual health knowledge and sexual experiences of people with LD, Study 2, which explored views of parents regarding sexual health knowledge and sex education of their children with LD and Study 3, which investigated experiences of teachers delivering sex education to people with LD.

3. Chapter Three

Study 1- Sexual Knowledge, Experiences, and Needs of People with Learning Disabilities

3.1 Overview

Shakespeare et al. (1996, p.23) in their book about sexuality and disability wrote: "There is quite an industry producing work around the issue of sexuality and disability, but it is an industry controlled by professionals from medical and psychological and sexological backgrounds. The voice and experience of disabled people is absent in almost every case." The aim of this study was to give voice to people with LD to explore their knowledge, experiences, and needs regarding sexual health and relationships.

3.1.1 Sexual health knowledge.

A comprehensive literature review regarding sexual health knowledge of people with LD can be found in Chapter 2.1. The results of previous studies were often contradictory, for example when it comes to the knowledge regarding specific areas of sexual health i.e. sexual interactions, or association between sexual experiences and knowledge. Overall, it would appear that knowledge of people with LD is highly variable, but often contains misconceptions. The topic of body parts appears to be best known, whilst knowledge of STIs and contraception, the least.

The assessment of knowledge is important so that the most appropriate and relevant material is included in sex education programs. Parents, teachers and other professionals need to know the details of knowledge held to support and educate people with LD adequately.

3.1.2 Sexual experiences and needs.

Literature reviews regarding people's with LD experiences and needs are outlined in Chapter 2.2 and 2.3. Results of previous studies suggest that most people with LD had developed friendships and relationships, and most expressed an interest in having such relationships. Many participants in those studies also reported sexual experiences. Details of people's experiences and wishes regarding relationships and sexual interactions are important in order to provide adequate support, write appropriate policies and procedures (for example regarding overnight

visitors in residential placements), design training programmes, and as a result of all these- reduce potential vulnerability of people with LD.

3.2 Purpose of Study 1

The aim of the study was to examine sexual health knowledge, experiences and needs of people with LD and sources of misunderstandings when it comes to the knowledge. Data from the study was analysed in two ways: quantitative and qualitative (Thematic Analysis, Braun & Clarke, 2006). The quantitative part of the study was based on the responses to the Sex-Ken questionnaire and was used to answer two research questions:

1. What is the level of knowledge about relationships, sexual interactions and sexual health among people with LD?
2. What sexual and relational needs, hopes and experiences do participants have?

The second part of the data analysis focused on qualitative analysis of the incorrect answers to the knowledge questions from the SexKen questionnaire. The aim of the analysis was to answer the following research question - What are the sources of errors and misunderstandings? Some considerations and suggestions are also given with regards to how to conduct interviews and design assessment tools in order to truly assess the details of knowledge held (see Chapter 3.7).

3.3 Method

3.3.1 Participants.

Twenty-seven individuals took part in the study (11 males and 16 females). The mean age was 40 years old (*SD* = 14.46). Information regarding the age of participants, IQ scores and sex are presented in Table 4. The participants had been living in four counties in the East of England. Information about sexual experiences and training of the participants was gathered from them as a part of the questionnaire. The sex of the participants was assessed by visual identification.

Table 4

Age, IQ score, sex and sexual experiences and education (SRE) of participants in Study 1

Participant Number	Age	IQ	Sex	SRE	Sexual experiences
1	14	69	Female	Yes	No
2	23	64	Female	Yes	No
3	24	49	Female	No	No
4	52	45	Female	No	No
5	50	57	Male	No	No
6	42	71	Female	Yes	Yes
7	46	57	Female	No	No
8	38	76	Male	No	No
9	54	63	Female	No	No
10	42	51	Female	Yes	Yes
11	51	61	Female	No	Yes
12	39	64	Female	No	No
13	40	53	Male	No	No
14	58	52	Male	No	No
15	23	62	Female	No	Yes
16	25	55	Female	Yes	No
17	35	63	Female	Yes	Yes
18	23	88	Male	Yes	Yes
19	35	58	Male	Yes	Yes
20	52	53	Male	No	No
21	17	49	Female	No	Yes
22	55	56	Male	Yes	No
23	45	55	Female	Yes	Unknown
24	55	68	Female	No	Yes
25	61	79	Male	Yes	Yes
26	61	68	Male	Yes	No
27	20	75	Male	Yes	No
Mean	40	61	M= 11, F= 16	Yes=13	Yes=10

No questions regarding the diagnosis or severity of disability were asked; neither any information regarding socio-demographic data (except for the date of birth) was gathered as the

only inclusion criterion was having LD, which was filtered by recruiting participants via specialist services and completing the IQ test. There was no assessment of adaptive skills. Based on the results of the Wechsler's Abbreviated Intelligence Scale (WASI-II, Wechsler, 2011) the mean IQ was M = 61.52 (SD = 10.28). The results suggest that five people had an IQ above 70 (IQ ranging from 71 to 88), 19 participants had a mild LD (IQ of 51- 69) and three participants had a moderate LD (IQ of 45-49). The results of the intelligence scale indicate that five participants had a borderline LD. However, all the participants attended services for people with LD and it can be assumed that they were assessed using more comprehensive tools to have a diagnosis of LD.

3.3.1.1 Recruitment.

As mentioned previously, initially, the study was going to focus on the knowledge and experiences of young people with LD and their parents' perceptions of this knowledge. I started the recruitment by making contact with the Mencap charity. Together with my first supervisor at the time, we met with the Research Officer, who made some comments regarding the design of the study and agreed to help with recruitment by posting information about it on their social media sites (Facebook and Twitter). They also sent emails to local group coordinators in East Anglia. At the same time, I attempted to recruit parents of children with LD via support groups in Cambridgeshire. However, no participants came forward.

In the next stage, I contacted all special schools and special educational needs units located by the mainstream schools in Cambridgeshire and asked for help with the recruitment. Only one school and one unit agreed to distribute information about my research amongst their pupils and parents and I was invited to give a presentation during a lesson for the students at one school as well. The remaining schools (7) did not reply to my messages or declined to support my research. I also contacted several day centres and residential services for people with LD in Cambridgeshire. One support provider agreed to distribute leaflets about my project. I also visited one residential unit to talk to the service users about my research. In addition, I was invited to the activities/groups organised by two-day centres and I talked to people about participation in my research. I also made a presentation about my project at two events organised by a local charity- Voiceability that provides advocacy and consultation services for people with LD. What is more, the information about my research was disseminated by the Service

Development Manager (Learning Disability), the Development Manager of Children's Disability Services and Parents' Partnership at Cambridgeshire County Council amongst staff working within the services, as well as all the care managers at the Cambridge Learning Disabilities Partnership. I also posted information about my research on forums and websites for people with LD and/or their parents. In the meantime, in order to improve the recruitment, I changed the inclusion criteria and increased the age of potential participants up to 25 years old, so that the study included young people, but those who could give consent for themselves.

It is impossible to know how many people exactly received information about my research as I was not always given evidence that something had been done (e.g. I was not included or copied in the emails sent out) or informed as to how many people the information was sent to by the people who agreed to help me with recruitment. Personally, I contacted around 30 organisations and schools. As a result of these efforts, I only completed interviews with two young people with LD and one mother.

To further improve the recruitment, I removed the upper age limit regarding potential participants with LD, so that potential adult participants could give consent themselves. In addition, as no parent-child pair agreed to take part in the research, the idea of interviewing both the parent and a child with LD was no longer pursued, which meant that the research questions had to be adapted as outlined in the general overview. A further ethics application was also made and accepted for introducing payments to participants. Final inclusion criteria for the study were that the participants had a known learning disability, were over the age of 13, and were able to communicate using speech.

Following the changes in design and inclusion criteria, I checked the county councils' websites for special needs and learning disabilities' directories (Cambridgeshire, Bedfordshire, Hertfordshire, and Norfolk). Appropriate organisations were then contacted via email outlining the research and asking for help. In total, 72 organisations were approached. Eight places agreed to help with my research by inviting me to do presentations/speak to their service users (I could not attend one event). In one organisation, staff members were going to speak to service users to see if anyone was interested. Two managers informed me that they would forward my request to their seniors.

Overall, the most successful method of recruitment was presenting at LD forums and advocacy groups. The learning disabilities' forums are meetings held quarterly in most counties gathering service users, professionals and carers (paid and family). Nine participants were recruited as a result of my presentations at the forums (one person took part in the meeting himself, two interviewees were told about my research by parents who witnessed me appearing at the forum and six people knew about the study from staff, who attended the events). Ten participants saw me talking about the research in the advocacy groups and seven at the day centre that they attended. One person, who took part in the study, was a stepdaughter of an acquaintance.

3.3.2 Materials.

The tools employed in this study consisted of The Wechsler Abbreviated Scale of Intelligence - Second Edition (WASI–II, Wechsler, 2011) and The Sexual Knowledge Experience and Needs Scales for People with Intellectual Disabilities (SexKen-ID) (McCabe, Cummins, & Deeks, 1999). In addition, a Participant Information Sheet, which was written using easy read format, with pictorial representations (see Appendix 1) was used. The consent form was also written using large font and simple sentences. The consent form had a separate page with a slip that could be used if people wished to withdraw from research at a later stage.

A few questionnaires that measure sexual health knowledge are appropriate to be used with people with LD. In the majority of previous studies investigating sexual health knowledge of people with LD, researchers used questionnaires developed for the particular study, with no or little attention paid to psychometric properties (e.g. Isler et al. 2009; Penny & Chataway, 1982; Timmers et al., 1981). Measurements with information about their psychometric properties are listed below. For assessment of some available tools and opinions of clinicians, see Thompson et al. (2016).

- **General Sexual Knowledge Questionnaire (GSKQ)** - Talbot and Langdon (2006) – revised and updated version of Bender Sexual Knowledge Questionnaire (1983).
- **Sexuality Knowledge, Experience and Needs Scale (Sex-Ken)** - McCabe (2000); used in the following studies: Szollos and McCabe (1995); McCabe and Cummins (1996);

McCabe (1999); Lockhart et al. (2010); Burns and Davies, (2011, only part of the questionnaire); Jahoda and Pownall (2014, questionnaire was used as a framework).

- **Socio-Sexual Knowledge and Attitudes Test (SSKAT)** - Wish, Fiechtl, and Edmonson (1977, as cited in, Edmonson et al., 1979); used in Edmonson et al. (1979); Robinson (1984); Niederbuhl and Morris (1993); Bambury et al. (1999); Michie et al. (2006).
- **Socio-Sexual Knowledge and Attitudes Tool-Revised (SSKAAT-R)** - Griffiths and Lunsky (2003) - an updated version of the SSKAT questionnaire; used in Lunsky et al. (2007); Lockhart et al. (2010).
- **Assessment of Sexual Knowledge (ASK)** – Galea et al., (2004).
- **Sexual Knowledge Interview Schedule (SKIS)** – Forchuk et al. (1995).

Out of the above tools, the SexKen- ID questionnaire is the most comprehensive as it has 244 questions. It has been used in many studies investigating the knowledge of people with LD in the past. It is recommended by the researchers in the field of LD (Grieve, McLaren, & Lindsay, 2007). The scale is designed to evaluate not only the knowledge, but also the experiences, feelings, and needs of respondents. Questions cover 13 different areas of sexuality: friendship, dating and intimacy, marriage, body part identification, sex and sex education, menstruation, sexual interaction, contraception, pregnancy, abortion and childbirth, sexually transmitted diseases, masturbation, and homosexuality (see Table 5). The SexKen has four parallel versions: SexKen- ID for people with mild LD, Sex-Ken- PD for people with physical disabilities, SexKen- C for caregivers of people with disabilities and SexKen designed for use in the general population. The tool allows the comparison of similarities and differences in the sexual health knowledge of different groups of respondents, for example it allows for the contrast of reports of people with disabilities with answers given by their caregivers. The measures may be completed as either a questionnaire or interview; however, it is recommended that the version for people with LD is completed in the form of an interview.

Each aspect (knowledge, feelings, experiences, and needs) can be tested separately. The version for people with LD is structured in such a way that it can be administered during three separate interviews. The authors of the questionnaire state that the topics of the subscales range from the least intrusive to the most private. At the end of each interview/part, there are

knowledge questions to determine if respondents have sufficient knowledge to proceed to the next part. The experience 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, or have yes/no format, scored 0 or 2 points. For the full questionnaire, see Appendix 2. Table 5 provides further details about each section. The results regarding the feelings subsection were not analysed as the most common answer to the majority of questions (e.g. How do you feel about your friends? How do you feel about being hugged like that? [re: pictures of clothed hugging]) was 'good' or 'ok', which is line with findings of Hartley and MacLean (2006) who noted response tendency to choose the most positive response alternative when presented with Likert-type scale. In addition, the knowledge and experiences of people with LD were the main foci of the study.

Overall, the main advantages of the tool are that it was designed for and tested with participants with LD, can be conducted as an interview, contains pictures and drawings, covers all aspects of human sexuality, uses a mixture of closed, open-ended and multiple choice questions and probes about experiences and needs as well as knowledge.

No scoring manual is available with the tool. Professor McCabe did not respond to my emails regarding the model answer sheet. A co-author of the scale, Professor Cummins, replied to my message saying that "the details of this scale have been lost in the sands of time" and suggested that I made my own scoring system (R. Cummins, personal communication, April 18, 2018). I then emailed some other researchers who have used the full version of the tool in the past and asked about the scoring manual used by them. Eventually, in my research, I used a scoring manual prepared by O'Callaghan and Murphy (2002) for their study. It provides guidelines and examples regarding the scoring of open-ended questions, for example in order to achieve 2 points for the definition of friendship, participants have to mention at least two of the attributes: to trust, choose to spend time with someone, to confide in, to share, to go out with someone. If one thing was mentioned, 1 point is awarded. Any other answer results in 0 points being given. For full scoring manual see Appendix 3. No instructions regarding administration of the SexKen tool are provided with it. In the recent review of available tools that could be used to assess the sexual health knowledge of people with LD, it was noted that there is a need for more guidance on administering of all of the tools (Thompson et al., 2016).

Table 5

Subscales, areas, range of scores and internal consistency coefficient (Cronbach's alpha) for the Sexual Knowledge, Experience, Feelings and Needs Scale version for people with LD (SexKen-ID, McCabe, Cummins, & Deeks, 1999)

Subscale	Area	Number of questions	Range of scores	Cronbach's alpha
Friendship (23 items)	Knowledge:	1	0–2	-
	Experience:	13	5–22	.73
	Feelings:	4	4–20	.34
	Needs:	5	5–25	.55
Dating and intimacy (16 items)	Knowledge:	2	0–4	.47
	Experience:	4	3–9	.72
	Feelings:	6	4–11	.79
	Needs:	4	4–20	.76
Marriage (16 items)	Knowledge:	2	0–4	.41
	Experience:	0	–	-
	Feelings:	13	6–10	.13
	Needs:	1	1–5	-
Body part identification (21 items)	Knowledge:	21	0–42	.96
	Experience:	0	–	-
	Feelings:	0	–	-
	Needs:	0	–	-
Sex and sex education (16 items)	Knowledge:	1	0–2	-
	Experience:	7	6–27	.68
	Feelings:	5	5–25	.72
	Needs:	3	3–15	.48
Menstruation (16 items)	Knowledge:	11	0–22	.74
	Experience:	2	2–4	-
	Feelings:	2	2–10	-
	Needs:	1	1–5	-
Sexual interaction (52 items)	Knowledge:	21	0–42	.66
	Experience:	15	8–31	.57
	Feelings:	14	8–31	.60
	Needs:	2	2–10	.86
Contraception (19 items)	Knowledge:	9	0–18	.83
	Experience:	8	4–11	-
	Feelings:	1	1–5	-
	Needs:	1	1–5	-
Pregnancy, abortion, and childbirth (24 items)	Knowledge:	15	0–30	.71
	Experience:	3	–	-

	Feelings:	4	4–20	.42
	Needs:	2	2–10	.77
Sexually transmitted diseases (19 items)	Knowledge:	11	0–22	.71
	Experience:	2	1–2	-
	Feelings:	4	4–20	.46
	Needs:	2	2–10	.57
Masturbation (16 items)	Knowledge:	3	0–6	.53
	Experience:	6	4–20	-
	Feelings:	6	5–25	.66
	Needs:	1	1–5	-
Homosexuality (10 items)	Knowledge:	1	0–2	-
	Experience:	1	1–5	-
	Feelings:	6	4–20	.01

According to the authors, the validity of the scale has been ensured through the initial development of the scale with close attention being paid to the wording of items and feedback from professionals working with people with LD, psychometricians, and participants from each group who completed the various versions of the scale. The authors also stated that the validity of the scale could not be assessed using another measure as no other scales existed at the time of development of the SexKen (McCabe, 2010). During the development of the scale, data from 60 people with mild LD was gathered. Test-retest data have been collected by the author of the scale on 30 participants with LD and can be seen in Table 6. The Test-Retest correlation coefficients for some of the subsections are low (.04 for Needs in Menstruation section), but those for knowledge questions vary from .23 for the Sex/Sex education subsection to .96 for Menstruation. Overall, SexKen is a reliable measure for the assessment of sexual health knowledge. The tool demonstrated high levels of internal consistency (Cronbach's alpha) for each of the subscales for each of the populations (general population, physical and learning disabilities) (McCabe, Cummins, & Deeks, 1999). The internal consistency coefficients for the SexKen-ID subsections can be seen in Table 5. The coefficients for the knowledge subsection varied from .41 for the Marriage to .96 for the Body Parts in the McCabes's study (1999). The overall internal consistency is acceptable. Problems and issues regarding the tool are discussed in more details in the Critical Reflections section (Chapter 3.5.3).

Table 6

Test-Retest reliability coefficients for all subscales of the SexKen-ID (McCabe et al., 1999)

Scale	Test-Retest Correlation Coefficient (*r*)	Scale	Test-Retest Correlation Coefficient (*r*)
Friendship		*Sexual interaction*	
Knowledge	.53**	Knowledge	79***
Experience	.60**	Experience	.84***
Feelings	.81***	Feelings	.77***
Needs	.80***	Needs	.52*
Dating and intimacy		*Contraception*	
Knowledge	.79*	Knowledge	.91***
Experience	.60**	Feelings	.82***
Feelings	.79***	Needs	.34
Needs	.79***	*Pregnancy/childbirth*	
Marriage		Knowledge	.80***
Knowledge	.54**	Feelings	.55*
Feelings	.41*	Needs	.72***
Needs	.75***	*STDs*	
Body Part		Knowledge	.68**
Knowledge	.79***	Feelings	.52*
Sex/sex education		Needs	.55*
Knowledge	.23	*Masturbation*	
Experience	.77***	Knowledge	.78***
Feelings	.87***	Feelings	.85***
Needs	.71***	Needs	.95***
Menstruation		*Homosexuality*	
Knowledge	.96***	Knowledge	.73***
Feelings	.38	Feelings	.19
Needs	.04	Needs	.59**

*$p < .05$; **$p < .01$; ***$p < .001$.

The knowledge questions in the SexKen questionnaire are either open-ended, with responses scored 0, 1, or 2 depending on the accuracy or completeness of the responses or 'yes-no' type ('Do children get pregnant?') scored 0 or 2 for the correct answer. The maximum number of scores on the knowledge questions is 196. The number of questions and maximum scores and example questions are presented in Table 7.

Table 7

The range of scores for the Sexual Knowledge Scale and examples of questions (SexKen-ID, McCabe, Cummins, & Deeks, 1999)

Subscale	Number of knowledge questions	The range of scores (min and max)	Example questions
Friendship	1	0–2	What is friendship?
Dating and intimacy	2	0–4	What is a date? What is meant by feeling close to someone?
Marriage	2	0–4	What is marriage? Prompt picture of a couple getting married
Body part identification	21	0–42	Label e.g. shoulder, breast, penis (on prompt pictures)
Sex and sex education	1	0–2	What is meant by having sex?
Menstruation	11	0–22	What is menstruation or periods? How often does a woman have her period?
Sexual interaction	21	0–42	What do you do if someone wants to kiss you or have sexual contact with you and you don't want to? How much semen does it take to get a girl/woman pregnant?
Contraception	9	0–18	What is contraception or birth control? If you wanted to get a condom, what would you do?
Pregnancy, abortion, and childbirth	15	0–30	How does a woman get pregnant? How is a baby born?
Sexually transmitted diseases	11	0–22	How do you catch sexually transmitted diseases? Should you tell anyone if you think you have a sexually transmitted disease or not?
Masturbation	3	0–6	What is masturbation? Prompt picture of man and woman touching their bodies
Homosexuality	1	0–2	What is homosexuality?

The Wechsler Abbreviated Scale of Intelligence (WASI–II), which has also been used in the study, provides a brief, reliable measure of cognitive ability for use in clinical, educational and research settings. The tool is recommended for psychologists and researchers as a quick and reliable measure when screening for learning difficulties (Wechsler, 2011). The WASI-II has a four- or two-subtest version. The four-subtest form (Vocabulary, Similarities, Block Design, Matrix Reasoning) can be administered in 30 minutes and the two-subtest form (Vocabulary and

Matrix Reasoning) can be given in about 15 minutes. As the test was used for screening purposes only and to minimise the time required to conduct the research, the two- subtest form was used in the study. In the Vocabulary subtest, participants are asked to give definitions for words, for example, “pet” or “bell.” The definitions are scored 2, 1 or 0 points depending on the accuracy and details provided. The subtest is discontinued after three consecutive scores of 0. In the Matrix Reasoning subtest, participants are presented with incomplete patterns and asked to complete them by choosing from possible options, for example there is a table with two apples in the top row and a banana alongside a question mark at the bottom and participants need to choose from five possible options, what needs to go in the place of the question mark. After three consecutive incorrect answers, the test is stopped. A very detailed manual including instructions and scoring guidelines is available with the tool.

The WASI-II presents excellent psychometric properties. Corrected split-half reliability coefficients for all composites met or exceeded .90 and test–retest reliability coefficients across 12 to 88 days were above .90 (Irby & Floyd, 2013). Validity evidence based on content was supported by the results from item try-outs, item scaling analysis, and item-bias analysis, but no detailed results of these analyses were provided in the test manual. WASI-II can be used with those with intellectual disability, intellectual giftedness, attention-deficit/hyperactivity disorder, learning disorders in reading or mathematics, and traumatic brain injuries (Wechsler, 2011).

3.3.3 Risk assessment.

Due to potential participants being vulnerable adults and young people and the sensitive nature of the research topic, a number of risks were identified, and precautions taken to minimize them were considered.

1. Some potential participants may lack capacity to consent to take part in the research.

One of the principles of the Mental Capacity Act 2005 is that “a person must be assumed to have capacity unless it is established that he lacks capacity” (MCA, 2005). I have completed training in the Mental Capacity Act. In a situation where there were any doubts as to participants’ ability to give consent, the procedure was not going to be continued.

2. There is a risk of disclosure of abuse, either by a person with a learning disability or a carer.

Before conducting the research, participants were informed that all information given would be kept confidential, except for the disclosure of potential abuse. Beforehand, I identified a person that would have to be informed of abuse and her/his name was given to participants with an explanation that I might pass information to her/him if there was a risk of abuse.

I have over 10 years of experience of working with vulnerable adults and children, and I am sensitive to issues of vulnerability and safeguarding. I have completed a number of trainings in safeguarding, and I am familiar with procedures for reporting potential abuse.

3. Research involves interventions with children and young people under 16 years of age.

Before asking adolescents for their consent, I obtained informed consent from their parents/ primary carers. The aims and procedures of the research were going to be explained to the young participants in a simple and clear way. The study would only continue if both parent/s and their children agreed to take part.

4. There is a risk of compromising the anonymity or confidentiality of personal, sensitive or confidential information provided by participants.

Confidentiality may need to be compromised in case of disclosure of abuse (see above).

In the findings of the research, I made sure that no names, places or any other information that could potentially help to identify participants were used.

5. Research involves direct contact with human participants.

The research involves discussing sensitive matters relating to human sexuality. Therefore, some participants may have become upset, distressed or embarrassed when discussing sensitive or difficult issues. All participants were given full information about the project before consenting to take part. Participants were also informed and frequently reminded that they had a right to stop completing the questionnaire or to withdraw completely from research at any point. The SexKen questionnaire is designed in such a way, that it moves from the least to most intrusive questions. Before completing each part, participants were asked if they were happy to proceed. Interviews with young people (under 16 years of age) were conducted with their parent/ carer nearby. In a situation where the young person with LD became upset, their parent, support worker or teacher, if the interview was at school, would be available to comfort them.

6. Risk to myself

There was also risk to myself as some interviews were completed in the participant's homes. To ameliorate the risk, I informed a designated person (family member or friend) of my whereabouts and logged in and out at the beginning and end of each session taking place at a participant's home.

3.3.4 Procedure.

Every interview started with the researcher reading an information sheet (detailing the nature and expectations of the project; see Appendix 1). Next, the consent form was read out to each participant, emphasising that participation was voluntary and the right to withdraw at any time. Participants were given a copy of the Participant Information Sheet (written in an easy read format) assuring them of confidentiality and anonymity in the case of publication of the results. It was made clear to the participants that in the event of an abuse disclosure, staff/parents would be informed, which was a safeguarding procedure. Next, participants were given the opportunity to ask questions about the study or their participation. If participants were happy to take part, they were asked to sign a consent form. All participants were able to sign the form. In the situation when the participant was under the age of 16, the above procedure was conducted with both interviewee and the guardian and two signatures required on the consent form.

Afterwards, verbal consent was sought for tape recording the meeting. The recorder was then turned on and put out of sight to reduce potential discomfort. In order to describe the sample correctly, the WASI-II (Wechsler, 2011) was completed with the participants. On average, it took 15 minutes to administer. Then, the outline of the Sex-Ken questionnaire (part of the tool) was read out and consent to go ahead sought again. The Sex-Ken questionnaire was then administered, in the form of an interview. All interviews lasted about one hour. The authors of the scale suggested that the interviews could take up to three hours. I believe the discrepancy was due to the fact that the authors suggested splitting the assessment into 3 interviews, which would require outlining the study and seeking consent on each occasion. All participants in my sample were given the opportunity to stop, have breaks and/or to complete the assessment on a second

occasion. Short breaks were practiced, but none of the participants expressed a wish to continue the interview on another day. All interviews were recorded and transcribed by myself.

Due to the sensitive nature of the topic, significant care was taken to minimise the risk of upsetting people or causing any discomfort. Before moving to each sub-section (topic), participants were asked for consent to go ahead. The authors of the SexKen recommend that consent is sought before moving to each of the main parts of the interview (3). Nevertheless, I found it better to ask for consent at the beginning of each sub-section. I would also frequently remind interviewees that they could pass a question and did not have to answer some or all of them. Eight people did not wish to answer some questions or sections. In Table 8, topics or specific questions that individuals declined to answer are listed. The list does not include cases when some questions were not asked due to the fact that participants showed no knowledge of the area. As there is no manual available with the Sex-Ken, it is unclear when the questions regarding certain topics should be stopped if the participant shows no evidence of knowledge on the topic. I made a decision that if no knowledge was evident after the first two questions in each section, which was usually a general type open-ended question and a prompt picture regarding the matter, for example in the Masturbation subsection, the first question is "What is masturbation?", followed by a picture of man and woman touching their bodies, then no further questions regarding the topic were asked. In the case of the WASI, most of the subtests are discontinued after three consecutive scores of 0. Therefore, a similar pattern was employed by me when administering the SexKen. As the safeguarding was the most important principle when conducting my research, extra care was taken not to cause any stress or discomfort to the participants. Hence, I believed that it would have been unethical and potentially harmful to continue asking questions on a topic not familiar to the participants. Assessing knowledge by asking for a definition of a term plus using a prompt picture, appeared to work well, especially for participants with limited verbal abilities, who might not be familiar with certain terms, but were able to recognise the activity/item presented in the picture.

The interviews took place in three types of locations: people's homes (eight in total: two of them being residential homes for people with LD, four people lived with their parents, and two interviewees lived on their own), in the day centres attended by the participants (eleven

interviews) and in a community centre where people were having advocacy group meetings (eight).

At the end of the interviews, participants were offered £10 cash payments as a gratitude for their time (except for P1 and P2 as the payments were introduced at a later stage). Participants had to sign a slip confirming that they received the money.

3.3.5 Data analysis.

Scoring took place using the transcripts and answer model sheet prepared by O'Callaghan and Murphy (2002). The inter-rater reliability of scoring done by me was conducted with two raters- Psychology PhD student (Rater 1, English being a second language) and a professional working with people with LD with a degree in Psychology (Rater 2, first language- English). The raters were asked to score a sample of the answers (one question from each of the subsections, except for Body Parts as it required pointing to the pictures, 12 in total) for five of the participants. Cohen's κ was run to determine if there was an agreement between the researcher and the two raters. There was a fair agreement between myself and Rater 1, $\kappa = .33$, $p < .0005$ and moderate for Rater 2, $\kappa = .58$, $p < .0005$, which is satisfactory (Viera & Garrett, 2005). Issues with scoring will be discussed further in Chapter 3.5.3.

In the situation when participants did not wish to answer a question or questions, unconditional mean imputation was used for the missing data when statistically analysing the results. In this method, for each variable with missing data, the mean for the non-missing cases is calculated and substituted for the missing data. Some argue that the mean imputation can lead to biased estimates of many parameters and more complex methods such as conditional mean imputation or multiple imputations are recommended (Allison, 2003). However, the results of the comparison of different methods of dealing with missing data conducted by Masconi, Matsha, Erasmus, and Kengne (2015) showed little difference between simple and more complex methods of imputation. If the participant was assessed not to possess knowledge of the area (as described in the procedure section), and no questions from the sub-section were asked, zero points were given.

Mean comparisons (*t* – tests) were conducted to check for difference between different groups (e.g. men vs. women) and Pearson correlation coefficients were calculated to investigate

associations between variables. All assumptions were checked and calculations were conducted using SPSS.

3.4 Results

3.4.1 Overall sexual health and relationships knowledge.

The mean sexual health and relationships knowledge score was $M = 102$ ($SD = 40$) out of a possible maximum of 196. In line with findings from previous research, the knowledge of participants was variable with the lowest score being 39 and the highest 171. See Table 8.

There was a moderate significant positive correlation (r (27) = 0.52, $p = .01$) between the knowledge scores and IQ scores. There was no correlation found between the age of the participants and the knowledge scores (r (27) = -0.07, $p = .70$).

Independent samples t-tests were conducted in order to see if there were any differences in knowledge between males and females, and between people who have or have not had sex and relationships education, and individuals who have and have not had sexual experiences.

The results suggest that there was no statistically significant difference in knowledge between females ($M = 104.13$, $SD = 40.97$, $N = 16$) and males ($M = 98.85$, $SD = 42.25$, $N = 11$); t (25) = .325, $p = .76$. Having sex and relationships education seems to be related to the knowledge regarding sexual health. Participants who reported having some form of a sex education scored significantly higher on the SexKen questionnaire ($M = 122$, $SD = 37$, $N = 13$) than those, who never had any education ($M = 83.4$, $SD = 35.90$, $N = 14$); t (25) = -2.75, $p = .04$.

Participants were classified as having sexual experiences if they reported encountering hugging with no clothes on or sexual intercourse. The mean achieved for the knowledge part of the Sex-Ken for those who reported having sexual experiences was significantly higher ($M = 137.3$, $SD = 30$, $N = 10$) than those who have not ($M = 80.93$, $SD = 32$, $N = 16$); t (24) = -4.47, $p < .01$.

Table 8

Participants' results and list of questions(Q) or sections (S) that participants did not wish to answer or when questions were not asked (NA)

Participant	Age	IQ	Sex	SexKen score	Did not wish to answer (Q- question, S- whole section) or questions on a topic not asked as did not possess the knowledge- NA
1	14	69	Female	68	NA: orgasm, contraception, STD, masturbation
2	23	64	Female	147	NA: STD
3	24	49	Female	82	NA: orgasm, contraception, STD, masturbation
4	52	45	Female	39	NA: menstruation, orgasm, contraception, pregnancy, STD, masturbation
5	50	57	Male	63	NA: orgasm, contraception, STD, masturbation
6	42	71	Female	167	
7	46	57	Female	68	NA: Menstruation, orgasm, contraception, masturbation
8	38	76	Male	95	Q: How often do you think about sex? How often would you like to have sex?; NA: Menstruation, orgasm, STD, masturbation
9	54	63	Female	79	NA: orgasm, contraception, STD, masturbation
10	42	51	Female	138	
11	51	61	Female	147.2	S: Masturbation
12	39	64	Female	46	NA: orgasm, contraception, pregnancy, STD, masturbation
13	40	53	Male	77.9	S: Body parts, Marriage, Sex and sex education, Sexual interactions, Masturbation (apart from definition); Q: Can people have sex without the woman getting pregnant?; NA: Menstruation, orgasm, contraception
14	58	52	Male	58	NA: menstruation, orgasm, contraception, STD, masturbation
15	23	62	Female	143	NA: STD, masturbation
16	25	55	Female	89	NA: orgasm, contraception, STD, masturbation
17	35	63	Female	143.8	Q: What happens when a man has an orgasm? What happens when a woman has an orgasm? What is ejaculation?
18	23	88	Male	156	
19	35	58	Male	83.5	Q: What is meant by having sex?, NA: menstruation, orgasm, pregnancy, STD, masturbation
20	52	53	Male	46	NA: menstruation, contraception, orgasm, STD
21	17	49	Female	86.5	Q: What do you do and talk about with your friends? What does it mean to have sex? Who should decide whether to have sex or not? How is baby born?, NA: orgasm, contraception, STD, masturbation
22	55	56	Male	148	
23	45	55	Female	85.7	S: Friendship, Dating, Body parts, Sex and sex education, Contraception, STI, Homosexuality, Q: What is this picture of? (hugging), What is this picture of? (hugging no clothes),What is this picture of? (kissing), What is sexual intercourse?, What is this picture of? (sexual intercourse), What does it mean to have an orgasm or to come?, Can a man have an orgasm?, Can a woman have an orgasm?, What happens when a man has an orgasm?, What happens when a woman has an orgasm?, What is ejaculation?, What is semen for?, How much semen does it take to get a woman pregnant?, Where do you do any of these things?, Where do other people do any of these things?, Where is it ok to do any of these things?; NA: pregnancy, masturbation
24	55	68	Female	137	
25	61	79	Male	171	
26	61	68	Male	78.8	S: STD; NA: menstruation, orgasm, contraception,

27	20	75	Male	110.2	S: Masturbation [a]; NA: menstruation, orgasm, STD
Mean	40	61	M= 11, F= 16	102	

[a] Questions from the section not asked due to mother being present.

When it comes to the participants not wishing to discuss certain topics, it would appear that questions regarding sexual intercourse, whether asking for a definition of it or personal experiences, were declined the most frequently. That could be because participants did not have knowledge regarding the topic, or they found it embarrassing to discuss. The questions from the following topics were not asked the most frequently due to assessment that no knowledge was held: orgasm, contraception, STDs and masturbation.

Participant 23 (female, 45) did not wish to answer the majority of the questions, however those questions that she did answer suggest that she had some knowledge regarding sex, hence mean imputation seemed to be a better option than deletion.

3.4.2 Knowledge by areas.

The section will cover analysis of the responses to the knowledge questions from the SexKen by topic. Please note that if an incorrect answer was given, this is reported. Errors will be examined in more details in Chapter 3.7. In the situation when the participant gave verbal ("don't know" or similar) or non-verbal indication of no knowledge (silence, shaking head etc.), this is reported as the participant not knowing the answer.

Friendship. There was only one knowledge question in the section- "What is friendship?" In order to be given 2 points for the answers, participants had to provide the following description: "to trust, choose to spend time with someone, to confide in, to share, to go out with someone (must mention at least two of these)". If participants mentioned the following descriptors: "to spend time with someone, or to trust someone, be friends forever (i.e.one of the statements)", they were given 1 point. Answers including statements, such as: "they are mates or go out", were scored 0 points.

Only six participants scored 2 points, seven participants gave answers worth 1 point, one person declined to answer the question (P23) and 13 participants provided answers, which were assessed not to fit any of the model answers. The incorrect answers included the following descriptions: P18 (male, aged 23): "It's when you have friendship with other people," P24

(female, 55): "Friendship is like I get on with everyone here, I do, that's friendship and that," P21 (female, 17): "Friends."

Several teachers, who took part in Study 3, mentioned that friendship was one of the better-known subjects by people with LD as it was taught to their students from early years and it was a part of everyday life. The surprisingly low mean for the question (M = 0.7) might be because the model answer required a sophisticated description of friendship. The above examples of "incorrect" answers suggest that people are familiar with the term and are aware of what it is regarding but may not have the vocabulary needed to provide a required answer.

***Dating and intimacy*.** There are two knowledge questions in the sub-section. The first question was: "What is a date?" In order to score 2 points for the answer, participants had to provide a detailed definition of a date: "attracted to a partner and going out with them (i.e. for a meal, to the cinema); partner of either sex, going out on a romantic date, the specification of place or date" according to the scoring manual. The following answers were awarded 1 point: "going out (romantic) with someone of the opposite sex or same sex or description of where one might go on a date." If participant mentioned "going out, with no specification of with whom or of romantic connotations, or a date as in the day, month, year etc.," he/she was given 0 points.

Three participants stated that they did not know what a date was and six provided answers not acceptable according to the scoring manual. Twelve participants scored 1 point, five participants 2 points and one participant did not wish to answer the question- P23. Once more, some of the answers, which were scored 0 points suggest that people were aware of the term, for example, P7 (female, 46) replied: "A date is romantic" and P8 (male, 38) said: "It's when you find a partner like the "Undatables", 'cause I watch them" but the answer provided by them did not fall into the scoring criteria as going out was not mentioned. Another participant (P13, male, 40) stated that he did not go on dates in response to the question. When asked what people did on dates, he replied "holding hands." One participant (P12, female, 39) replied "it's Thursday" when asked what a date was.

The second question in the sub-section was: "What is meant by feeling close to someone?" If participants mentioned: "feeling attracted to someone and/or being able to trust/ confide in someone and/or enjoying being with someone- at least 2 of the 3," they were awarded

2 points. An answer: “you like someone or trust confide in or feels nice to be with/ they’re important,” resulted in 1 point given.

The question proved to be difficult for the majority of the participants (14), who scored 0 points. Only three participants provided answers worth 2 points. Nine participants provided answers, which fitted the criteria of score 1. Out of the answers, which were assessed to score 0 points, three participants stated that feeling close to someone meant kissing (P3, P12, P24), four participants said they did not know what it was, and the rest (7 participants) gave answers suggesting that they were aware of the phenomenon, but their answers did not fit the stated criteria, for example, P14 (male, 58) said: “When I see [name of the girlfriend] on Saturday, I make her a cup of tea.” One person did not wish to answer all the questions from the section (P23).

Marriage. Participants could score 4 points for two knowledge questions in the section. The first question was “What is marriage?” and the second- a prompt picture representing a couple getting married. An answer worth 2 points to the “What is marriage?” question needed to include at least two attributes of marriage: “vows, ceremony/ wedding, commitment to partner, ring.” When participant mentioned: “commitment to partner for life or wedding/ceremony or buying of ring or vows “(i.e. one of these mentioned), 1 point was given. An answer “getting together” or any other not mentioned above resulted in 0 points.

One person (P13, male, 40) did not wish to discuss the topic, as he “did not like marriage.” Four participants scored 0 points when asked what marriage was. Participant 4 (female, 52) stated that “you get married to your dad,” P12 (female, 39) said that she did not know about marriage, P14 (male, 58) replied “my sister” and P23 (female, 45) responded that she “was not getting married” and when prompted stated it was difficult to explain. The rest of the participants mentioned one or two attributes of marriage (vows or ceremony/ wedding/ commitment to partner/ring) and scored 1 (14 participants) or 2 points (8).

When it comes to the prompt picture, participants needed to recognise the activity and label it as: “marriage (getting married) or wedding, or bride and groom,” in order to gain 2 points or “man and woman together or mention of church” to achieve 1 point.

All participants correctly identified the activity presented in the prompt picture, with the majority of participants (24) gaining 2 points. Participant 18 (male, 23) replied that the picture presented "a man and a woman" and P9 (female, 54) said: "partners, a couple," which meant that they were given 1 point.

***Body part identification*.** The section consisted of 21 questions, each worth 2 points. Two prompt pictures were used. One presented a dressed man and woman and the second one undressed people of both sexes. Participants were asked to identify sexes of the figures- "Which is the man, and which is the woman" (with and without clothes). Next, the participants had to point correctly to the body parts (eyes, nose, leg, belly button, bottom or buttocks, feet, penis, chest, ankles, arm, shoulder, mouth, breasts, neck, hips, nipples, hands, vagina, back) using the picture of undressed people as a prompt and mention function of it, apart from the belly button, in order to receive 2 points. If the correct label or definition was mentioned, the participant was given 1 point.

All the participants (two people did not wish to answer questions from the section- P13 and P23) correctly identified the sexes of the dressed figures. When it came to pictures of undressed people, one participant (P5, male, 50) incorrectly pointed to drawings of the man and woman without clothes and the rest of the participants (24) gave correct answers.

The knowledge regarding private/ sexual organs is presented in Table 9. In order to score 2 points participants needed to correctly point to the body part in the picture and give a definition of it e.g., "bottom is for sitting or going to the toilet." The scoring manual only accepted sexual functions of mouth, penis and vagina, for example, the definition of mouth must "include kissing," and that of penis and vagina needs to "mention sexual intercourse or other term used to describe heterosexual or gay sex." When it comes to the definition of the breast, it needed to include "breastfeed or foreplay," with the latter function not mentioned by anyone and the definition of the nipples should incorporate "for babies (to suckle)."

Three participants were not able to label the penis and vagina and only one participant (P6, female, 42) mentioned the sexual function of the penis. Nobody included kissing as a function of mouth but rather concentrated on its function for eating or breathing.

Table 9

Participants' answers regarding identification and functions of body parts (2= the label and function, 1= label only).

Participant	Identify sexes (dressed)	Identify sexes (un-dressed)	Label/ function bottom	Label/ function penis	Label/ function mouth	Label/ function breasts	Label/ function nipples	Label/ function vagina
1	2	2	2	1	1	2	2	1
2	2	2	2	1	1	2	1	1
3	2	2	2	1	1	1	1	1
4	2	2	2	0	1	1	2	1
5	2	0	0	0	1	0	0	0
6	2	2	2	2	1	2	2	1
7	2	2	2	1	1	2	1	1
8	2	2	2	1	1	2	0	1
9	2	2	2	1	1	2	0	1
10	2	2	2	1	1	2	1	1
11	2	2	2	1	1	2	1	1
12	2	2	0	0	1	2	0	1
13	2[a]	1.9[a]	1.7[a]	0.9[a]	1[a]	1.5[a]	0.8[a]	0.9[a]
14	2	2	0	1	1	1	0	0
15	2	2	2	1	1	1	1	1
16	2	2	2	1	1	2	1	1
17	2	2	2	1	1	2	1	1
18	2	2	2	1	1	1	1	1
19	2	2	2	1	1	1	1	1
20	2	2	2	1	1	1	0	0
21	2	2	2	1	1	1	0	1
22	2	2	2	1	1	1	1	1
23	2[a]	1.9[a]	1.7[a]	0.9[a]	1[a]	1.5[a]	0.8[a]	0.8[a]
24	2	2	2	1	1	2	2	1
25	2	2	2	1	1	2	2	1
26	2	2	2	1	1	1	0	1
27	2	2	2	1	1	2	1	1

[a] P13 and P23 did not wish to answer the questions from the section and therefore the missing data was substituted with a mean of the non-missing.

Sex and sex education. There is one knowledge question in the section- "What is meant by having sex?" and participants needed to provide "a description of sexual acts/ penetration of vagina/ anus/ sexual acts with a partner" in order to gain 2 points. If participants mentioned

"going to bed with someone, sexual intercourse/ being intimate with someone," they were given 1 point.

Four participants did not wish to answer the question; three provided a good description of the sexual act and six participants scored 1 point. Seven participants replied that they did not know what sex meant. Two participants believed it meant "getting married" (P1, female, 14 and P4, female, 52). The rest of the answers scored 0 points (5 participants) included: "a man" (P3, female, 24), "snogging, sex means to have sex on your lips" (P8, male, 38), "it's how you can have a baby" (P16, female, 26), "two people cuddling each other" (P26, male, 61). Participant 5 (male, 50) responded to the question in the following way: "a woman and man, if they want sex, they can have sex."

Menstruation. Overall, there are 11 knowledge questions in the sub-section, but three questions are aimed at women, who had started their periods, only. The first knowledge question in the sub-section is "What is menstruation or periods?" In order to be given 2 points for the answer, the participants needed to provide the following definition: "a woman's release of blood/ the lining of the womb/ a woman's menstrual cycle/ woman bleeding once per month to get rid of the lining of womb/ bleeding from the vagina." An answer worth 1 point consisted of: "blood coming out (description of losing blood)."

Only two participants scored 2 points (P10, female, 42 and P25, male, 61). Eleven participants achieved 1 point (2 males: P18, aged 23 and P22, aged 56). Just over half of the participants (14) scored 0 points, either because they did not know what menstruation or a period was (3 females, 6 males) or gave a definition, which did not match the criteria of model answer: "it's a girly thing" (P3, female, 24), "it's what you have" (P16, female, 25), "if they're on or not" (P5, male, 50), and "I had it before and I was having cod oil tablets and I was having hot water bottle" (P9, female, 54). Participant 13 (male, 40) gave the following answer: "they are bad (…) That's women's problem, not men's".

The prompt picture of sanitary towel and tampon, which was part of the tool, was of a very poor quality and black and white. I used a coloured picture of better quality, presenting the same products and was using both pictures. If participants recognised both objects, they were given 2 points and when one - 1 point.

Ten participants identified both tampons and sanitary towels and five participants correctly named one of them. The incorrect answers in response to the picture included cigarettes (P12, female, 39 and P9, female, 54) and rolling pin (P4, 52 female and P5, male, 50). The rest of the participants (8) did not know what the pictures presented.

The next question was asking "What they were for [sanitary products]?" If participants said: "to collect a woman's blood during a period," they were given 2 points and when "period" was mentioned, 1 point was awarded. Eleven participants (2 males, P18 and P25) provided answers worth 2 points and further four (1 male- P22) scored 1 point. The remaining 12 participants did not know what the pictures were of.

The following question was: "Can you tell me how to use them [sanitary wear]?" In order to be awarded 2 points, participants had to show knowledge of how to use both products: "tampax- insert /put into vagina, sanitary towels- put them in your knickers." If participants displayed knowledge of how to use only one of the sanitary wear or stated: "put them up there/ soak up blood," they were given 1 point.

Thirteen out of the 15 participants who knew what sanitary products were, could explain how to use both of them (10, 1 male- P25) or one (3, females only). The remaining two males (P22 and P18) who knew what sanitary towels and tampons were, did not know the answer to this question.

The next question asking "Why does a woman have a period?" required a detailed answer and proved to be difficult. The answer worth 2 points needed to include: "to discharge the lining of the womb, which has formed for the fertilised eggs to attach to." In order to achieve 1 point, participants had to state that "because she has not fertilised the eggs/ become pregnant."

Only one participant (P25, male, 61) gave an answer, which matched the model answer, scored 2 points and further four (1 male- P18) scored 1 point. Nine participants were not asked the question as they did not know what periods were and could not identify sanitary products on the picture and thirteen participants did not know the answer to the question. Participant 5 (male, 50) stated in response to the question: "When she's on period, it upsets us. If she's not on period, then yes, we can."

The next question from the subsection was “How often does a woman have a period?” Two points were awarded for the answer: “every 28 days/ once a month” and 1 point for “about every 2 months/ a few times a year/ about every 3 weeks.”

Fourteen participants were aware how often women had menstruation and scored 2 points. Nine participants were not asked the question. Two participants responded “don’t know,” participant 23 (female, 45) said: “twice a week” and participant 3 (female, 24) thought that it was “once a week.”

The next two questions were “yes/no” type of questions: “Do men have periods?” and “When a woman has her period, does the blood come out of the same hole where the urine comes out?” If participants provided correct answers (“no”), they were given 2 points.

All 18 participants, who were asked the question if men had periods, knew that only women had them. Only two participants (P2, female, 23 and P21, female, 17) knew the answer to the second question. However, as the question was a “yes/no” type and there were no follow up questions to verify the knowledge, the correct answers could be due to a guess. The remaining 16 participants did not know the answer to this question.

Fifteen women were asked three questions aimed at females only. Participant 1 (aged 14) had not started her periods and therefore was not asked the questions. The first question was: “What do you do when you get your period?” If participants “display knowledge of using sanitary wear,” 2 points were given. In the situation when statement such as “use those things (not explicit knowledge)” was mentioned, 1 point was awarded. Answers including “get paid/ don’t know/ nothing” were scored in 0 points. Eleven females knew what to do when they had their periods (three participants scored 1 point and eight- 2 points). Two of the participants (P9, 54 and P12, 39) replied that they had to take paracetamol and a further two did not know what to do.

The next question- “Do you know when your period is due or not?” was a “yes/no” type, with the response “yes” awarded 2 points, “sometimes”- 1 point and “no”- 0 points. Nine females knew when their menstruation was due and six did not.

The answers to the next question –“What would you do if your period didn't come?” needed to include the following information: “tell doctors/ staff/ parent/ carer” in order to be

given 2 points, “tell friend” was awarded 1 point and “nothing/ don’t know” – 0 points. Ten participants were aware that they had to tell staff, family, or a doctor/nurse that their period did not come. Participant 21 (17 years of age) replied that it would be “fabulous” if her period did not come and she would not be worried, and Participant 16 said she would be “glad.” The rest of the participants (3) did not know what to do.

Sexual interactions. The sub-section consists of four prompt pictures with different activities being represented- hugging, cuddling without any clothes on, kissing and sexual intercourse and 17 open-ended or yes/no type of questions, making it 21 knowledge questions in total. Participants were asked about each picture first (“What is this picture of? What are they doing?”) and then probed about their experiences and feelings about the activity, for example kissing. The first prompt picture presented a dressed man and woman hugging each other. In order to score 2 points, participants had to recognise the activity as: “hugging/ holding each other/ holding arms or hands/ embracing.” If participants said: “they’re close/ together,” they were awarded 1 point. Any other answer was scored 0 points.

Twenty- five participants correctly recognised and described pictures presenting two people hugging and scored 2 points. Participant 3 (female, 24) replied “kissing”, which was awarded 1 point and Participant 20 (male, 52), who said “man and a lady” scored 0 points.

The second picture portrayed a couple hugging each other with no clothes on. An answer: “embracing/ hugging/ kissing/ foreplay” resulted in 2 points given whilst “holding” in 1 point. All 27 participants answered the question correctly and scored 2 points.

The third picture was of a man and woman kissing. Answers worth 2 points consisted of: “snogging/ kissing/ French kissing.” If “closeness/ getting off with each other” was mentioned, 1 point was given. Again, all the participants correctly recognised the activity presented.

When shown a picture of a couple having sexual intercourse, participants had to recognise the activity as: “sex/ sexual intercourse” in order to be awarded 2 points, “shagging/ man and woman together, naked” resulted in 1 point. If participants said: “man and lady laying down/ don’t known/ other incorrect answer,” they achieved 0 points.

Nineteen participants knew that the picture presented a couple having sexual intercourse and scored 2 points. Out of the seven participants, who scored 0 points, four said that they did

not know what it presented, P1 (female, 14) said that they were “hugging each other,” P5 (male, 50) responded: “that's a hand and there's foot and that's a head. Cuddling” and P26 (male, 61) described the picture in the following way: “Right, they are lying down and both having a cuddle, saying something, whatever. The woman's touching man's knee in certain position.”

The next set of questions was regarding orgasms. The first question was: “What does it mean to have an orgasm or to come?” The correct answer, worth 2 points needed to include: “climax of sexual excitements/ to reach the peak of excitement (in sex)/ to climax and ejaculate (release fluid).” If participants mentioned: “to be excited, use of other expression referring to orgasm,” 1 point was given. “Don’t know” or “incorrect response, i.e. release of blood” resulted in 0 points.

Only three participants were able to explain well what orgasm meant and scored 2 points, a further five participants scored 1 point and one person did not wish to answer the majority of the questions from the section (P23, female, 45). Two participants (P2, female, 23 and P10, female, 42) stated that they heard of an orgasm, but could not explain what it meant. The majority of the participants (16) did not know what orgasm was or never heard of it. There were many misunderstandings regarding it. For example, P26 (male, 61) said:

“P26: It's something to do with… hmm... with what woman have, isn't it?

I; Just woman have orgasms?

P26: Yea.

I: And do you know what happens to a woman when she is having an orgasm?

P26: It may mean that she ends up being pregnant.”

The next two questions: “Can men have an orgasm? Can women have an orgasm?” were a “yes/no” type with the correct answer (“yes”) scored 2 points. There were no follow up questions that would help to recognise if the correct answer was due to knowledge held or a guess. Nine participants knew that men could have an orgasm and ten that women could have it. Participant 11 (female, 51) and Participant 26 (male, 61) expressed an opinion that only women could have an orgasm and P24 (female, 55) believed that only men could. Sixteen participants were not asked the question as they were not aware of the terms (orgasm/ to come).

Only people who knew the answer to the previous questions (10 participants), were asked the next two questions. “What happens when men/women have an orgasm?” In the situation when participant believed that only men/women could have an orgasm, they were asked about that sex’s reaction. The correct answers (scored 2 points) regarding men’s orgasm needed to include the following: “he ejaculates/ he releases sperm or semen/ he comes with pleasure of excitement.” An answer worth 1 point consisted of: “he gets excited/ he moans with excitements/ his penis is hard/ erect.” Responses about female’s orgasm worth 2 points needed to include: “she comes with excitement, releases fluid.” If “she gets excited/ she moans with excitement” were mentioned, 1 point was given.

Six participants knew what happened when men had an orgasm, with three participants scoring 2 points and three- 1 point. Five participants explained what happened when women had an orgasm (three answers worth 2 points and three- 1 point). Interestingly, only three participants (P6, female, 42, P10, female, 42 and P25, male, 61- all had had sexual experiences) were aware of the reactions of both sexes. Three participants only knew what happened when men had an orgasm (P22, male 55, P18, male, 23 and P24, female, 55) and two only when women (P11, female, 51 and P2, female, 23). The remaining participants (4/5) did not know the answers to the questions.

The next question: “What is ejaculation?” required the following answer to achieve 2 points: “ejection of fluid from female or semen from male/ release of fluid at the height of sexual excitement.” One point was awarded if participants said: “when a man or woman comes/ sexual excitement.” Only two participants knew what ejaculation was (P18, male 23 and P25, male, 61) and scored 2 points. The rest of the participants did not know the answer to the question (24).

The next question was: “What is semen for?” Participants needed to state that it was: “reproductive fluid that carries sperm in males/ used to fertilise the female egg and make women pregnant” in order to score 2 points. Answer “to go inside a woman to make babies” resulted in 1 point given. Two participants provided answers worth 2 points (P25, male, 61 and P27, male, 20) and a further seven participants were awarded 1 point. Seventeen participants were not aware of what semen was.

The following question- “How much semen does it take to get a girl/woman pregnant?” proved to be a difficult one. Answer scored 2 points was: “1 sperm/ a very tiny amount” and 1

point- “not much.” None of the participants were aware that it took a very tiny amount of semen to get women pregnant and only two participants said “not much” and scored 1 point (P2, female, 23 and P17, female, 35). Seventeen participants who did not know what semen was, were not asked the question. Five people replied that they did not know and two did not respond correctly. Participant 11 (female, 51) said: “Quite a bit I think” and Participant 22 (male, 55): “Loads I would think.”

A further three questions were regarding the understanding of where it was acceptable to have sexual interactions. The first question was: “Where do you do any of these things?” The question did not specify what “these things” meant and as it was asked after the questions regarding sexual experiences, it could mean different activities for different people. In the situation when I had to clarify the question, I would refer to behaviour depending on people’s experiences, for example kissing or sexual intercourse. The answer “TV room/ anywhere” was scored 0 points, 1 point for “lounge” and 2 points for “bedrooms/ bathrooms private place.” The next two questions: “Where is it ok to do any of these things?” and “Where do other people do any of these things?” were scored either 2 or 0 points. Two points were awarded if the answer was: “bedroom/ bathroom/ private place/ lounge etc. if privacy mentioned” and 0 points if the answer included “public place or don’t know.”

The majority of the participants (20) showed an understanding of private/public places and knew where it was acceptable to have sexual interactions and where other people did it, with the answers being “bedroom” or “in private.” Five people stated that they did not know where it was ok to do it and Participant 20 (male, 52) gave the following answer:

“I: Where do you kiss and cuddle?

P20: Sun room. Hard.

I: When you go out with [name of the girlfriend]...

P20: Restaurant.

I: Yes, like to a restaurant, would you kiss and cuddle her in public, like in the restaurant?

P20: Yes, restaurant.

I: Is it ok to do it when other people are around?

P20: People.

I: Or is it better to do it when it's just the two of you?

P20: Don't mind."

The next four questions were assessing people's knowledge of how to stay safe and their rights. The required answer scored 2 points, to the first question: "What do you do if someone wants to kiss you or have sexual contact with you and you didn't want them to?" needed to include "tell them 'no'/ tell them you don't want to." If participants stated that they could "say 'no', but apologise for this or give in/ ask them to wait/ put them off," they were awarded 1 point and if they believed that they had to "say 'yes' or OK even though you don't want to," 0 points was given. The majority of participants (23, 85%) knew that they had the right to say "no", four participants were not sure what to do (P1, P4, P12 and P20).

The next question was enquiring about people's reactions to unwanted contact: "What do you do if someone did kiss you or have sexual contact with you and you didn't want them to?" The answer worth 2 points needed to consist of: "say 'no' and push them away/ report them to the police/ parents/ carer." If participants mentioned: "tell someone/ tell them it was wrong", 1 point was given. Answers such as: "let them do it and don't report it/ feel sorry for them/ get upset, but don't tell anyone/ don't know/ nothing" were awarded 0 points.

Four participants (P1, P4, P12 and P20) replied: "I don't know" and 20 participants provided answers worth 2 points. Some participants provided very detailed descriptions of what they would do, for example, Participant 13 (male, 40) stated that such behaviour was "attacking" and he "would kick them in privates and leave them and run." He also mentioned calling the police. Three participants scored 1 point (P5, P7 and P16). Participant 5 (male, 50) replied: "what's wrong with touching or kissing?!" in response to the question. When it was explained that if it was consensual, there was nothing wrong, but a situation when one person did not wish for it to happen was discussed, he said: "if that person wants to, but another doesn't, that person can go and sit next door." After further prompting, the participant added: "I would probably tell one of the staff. I haven't done anything wrong." The response suggests some understanding of people's right to say "no" and the need to report it, but it is unclear which "person should go and sit next door" and the acknowledgement that such behaviour was not acceptable was not

apparent, therefore 1 point was given. Similarly, Participant 16 (female, 25) said: “I wouldn't mind them kissing me, that's ok.” Again, after emphasizing that unwanted contact was being discussed, she stated that she “would say ‘no”’, but after further prompts and giving an example of her being kissed on the street by a stranger and asking about her reaction to it, she stated that she “would be a bit disappointed.” As the answer suggests a limited understanding of rights and consent, 1 point was awarded. Participant 7 (female, 46) responded: “I would say ‘no’. I would feel a bit frightened” and she did not feel that any further action was needed, hence 1 point was given.

The next question: “Can you say ‘no’ to someone who wants to kiss you?” was a “yes/no” type, with the answer “yes” worth 2 points. One participant stated that she was not sure (P12, female, 39) and two participants said “no” (P4, female, 52 and P20, male, 52). The rest of the participants (24) were aware of their right to say “no.”

In order to be given 2 points for the answer to the next question: “How do you say ‘no’?” participants had to show that they would say: “’no’ firmly/ I don’t want to (it’s my choice)/ shout at them (if necessary).” If participants believed that they could “say ‘no’ apologetically (as if with no right to)’, they were awarded 1 point. An answer “can’t say ‘no’/ don’t know”, was scored 0 points. Twenty-four participants were awarded 2 points and the three participants who did not know the answer to the previous question (P12, P4 and P20) were not asked the question.

The last knowledge question in the subsection was regarding people’s awareness of consent to engage in sexual activity (“Who should decide about whether you have sex with someone or not?”). An answer: “I should/ my partner and I should (showing rights of personal choice)” was worth 2 points and responses such as “it’s up to my partner/boyfriend/ girlfriend/ it’s up to the staff/ it’s up to my parents (showing that having sex is someone else’s choice and not the individual responding)” was worth 0 points.

Thirteen participants (50%) knew that it was up to them or them and their partner to decide if they wanted to have sexual contact. One participant did not wish to answer the question (P21, female, 17). Seven participants said they did not know the answer to the question. Participant 3 (female, 24) believed that staff should decide, Participant 14 (male, 58) replied: “I would report it to the staff” and four participants thought that women should decide whether to have sex or not (P5, male, 50, P6, female, 42, P17, female, 35 and P26, male, 61).

***Contraception*.** The section consists of nine knowledge questions (two prompt pictures- a drawing of a man putting a condom on and a picture of pill, cap/coil and condom), with five of them concentrating on knowledge of condoms. The first question enquired if participants knew what contraception or birth control was. In order to be given 2 points, participants had to provide the following definition- "a means of preventing pregnancy." Answer scored 1 point was "condoms/ pill (name of other contraceptive device)."

Twelve participants knew what contraception was, with six of them providing a correct definition (2 points) and a further six naming a contraceptive device (1 point). One person did not wish to answer questions from the section (P23, female, 45). Participant 7 (female, 46) replied: "my mum gave a birth to me" in response to the question. Thirteen participants stated that they did not know what contraception was. It would appear that despite having two synonyms – contraception and birth control in the question (I always used both), some participants were not familiar with the terms, but had some knowledge about protection and knew about condoms. For example, P3 (female, 24) did not know what contraception or birth control was, but reported that condoms were to "have sex with" and "stop you being pregnant." Excerpt from Participant 9 (female, 54, see below) also suggests that not knowing the term contraception or birth control was not equal to not having the knowledge or using protection when having sexual contacts.

"I: Can we talk about contraception?

P9: No, I don't have any.

I: Do you know what contraception is?

P9: No.

I: Do you know what birth control is?

P9: No.

I: You know the implant you have got- that's contraception. Why do you have your implant? [the fact of having an implant was disclosed earlier in the interview]

P9: Cause I don't want to have any babies."

In response to the second question in the section ("What is a condom?"), participants had to say: "a contraceptive sheaths/ a rubber sheath/ something a man puts on his penis to prevent pregnancy or spread of STDs (display knowledge of appearance and function)" in order to be given 2 points. An answer: "put it on a man's penis/willy, it's a rubber/ like a balloon/ stops pregnancy (i.e. appearance or function)" was awarded 1 point.

Nine participants scored 2 points as they displayed knowledge of the appearance and function of a condom and further six mentioned one of them and scored 1 point. Eleven participants did not know what a condom was (one person did not wish to proceed to the section- P23).

The next task was to recognise/ describe the drawing of a man putting a condom on. The following description: "a man putting a condom/ rubber sheath on" was awarded 2 points. An answer: "a man's penis with a 'thingy' on (to stop babies or indicates knowledge of purpose of a condom)" was worth 1 point. Zero points was given if participants mentioned: "a penis/ other description of male genitals, not mentioning the condoms, a man holding his penis/ a man masturbating/ don't know or other incorrect response."

Fourteen participants correctly described the drawing and received 2 points. Three participants said they did not know what the picture represented (P1, female, 14, P4, female, 24 and P12, female, 39). Ten participants stated that it was a drawing of a penis/ man holding a penis and did not mention the condom.

Only 15 participants, who answered at least two of the above questions correctly, were asked the next question ("What is condom for? /What does it do?"). In order to receive 2 points for the answer, participants had to mention prevention of pregnancy and protection from STIs (two functions) or one of the functions to achieve 1 point. Seven participants scored 2 points and seven- 1 point. Participant 10 (female, 42), who knew what a condom was ("a rubber") and correctly identified the activity on the prompt picture (2 points), when asked about its function replied: "For a man (…) to put on his penis" and scored 0 points.

In response to the next question- "If you wanted to get a condom, what would you do?" participants had to state: "family planning clinic/ chemists/ supermarket/ public house toilets/doctors" in order to be given 2 points. If "ask someone/'go to doctor" was mentioned, 1

point was awarded. All fifteen participants who were asked the question knew where to get a condom from and received 2 points.

The next question- "Describe how to put on a condom" required the participants to provide the following description in order to be given 2 points: "take out of packet and squeeze the end to release air, stretch and roll down over erect penis (descriptive account of how to put a condom on)." An answer: "put it on the penis/ willy (no description of how)" was worth 1 point. Out of fifteen people who were asked the question, seven participants scored 2 points, four participants were given 1 point and four participants stated that they did not know how to put the condom on.

The last three knowledge questions in the section were regarding other means of contraception. In response to the question- "Can you name any other things you can use for birth control?" participants had to name at least two other devices, for example: "the pill/ cap/coil/ femidom." If one thing was named, 1 point was given. Again, only 15 participants who knew what contraception/ a condom was were asked the question.

Nine participants could name two things that could be used for birth control and three participants mentioned at least one. The most commonly mentioned contraceptives were pills and implants. Three people could not name any.

The next task required that the participants recognised contraceptives (at least 2 of the 3: the pill/ the cap/coil and condom) in the picture. The Sex-Ken picture was of a very poor quality (black and white). I printed a coloured one representing the same contraceptives and was using both of them as prompts.

Thirteen participants correctly identified the pill, condom and a cap/coil from a picture (11 participants at least two devices and two participants – one contraceptive). Two participants (P26, male, 61 and P22, male, 55) said that they did not know what the picture represented.

The last question from the section was- "What are they used for? [contraceptives from the picture]." If participants stated: "to prevent pregnancy and/or control periods," 2 points were given. If only "to protect you" was mentioned, 1 point was awarded. All thirteen participants who recognised contraceptives on the picture knew what they were used for and scored 2 points.

***Pregnancy, abortion, and childbirth*.** There are 15 knowledge questions in the section, including two prompt pictures- a pregnant lady and a woman giving birth. The first question- "What is pregnancy? What does it mean to be pregnant?" required very detailed answer according to the scoring manual: "development of the child or the young in the womb/ when a female carries a child inside (the womb)/ fertilisation of the egg by the sperm to make a baby that the woman carries inside" in order to score 2 points. An answer: "having a baby/ baby in the tummy/ going to have a child (refers to having a child without mentioning the womb)' was awarded 1 point.

Only two participants provided an answer worth 2 points (P6, female, 42 and P25, male, 61). A further 14 participants knew what pregnancy was, but provided a simpler response (i.e. having a baby/ baby in the tummy, which was scored 1 point). Six participants said that they did not know what pregnancy was. Participant 27 (male, 20) provided the following answer: "females get pregnant and in a couple of months' time, their belly starts growing slowly in months and months' time." Participant 26 (male, 61) stated that pregnancy was: "something that's inside woman's body that goes round and round and things like that. You get morning sickness and so on. What's the other thing?…err… morning sickness, something that goes round and round in the circle. Woman's tummy gets bigger, that's it." Participant 21 (female, 17) said in response to the question: "my mum was pregnant with me. It was really painful for my mum." Participant 8 (male, 38) replied: "when a man and a lady have too much sex that means that they can get a baby" and Participant 7 (female, 46): "I have a big tummy, but I can't yet." All the quoted replies were scored 0 points.

Next, the participants were shown a picture of a pregnant woman followed by a question: "What is this a picture of?" An answer: "a pregnant woman/ a woman who is having a baby" was worth 2 points and "baby in tummy"- 1 point. If participants stated: "I don't know/ big tummy/ stomach/ fat/ incorrect response" no point was given.

Twenty participants correctly described the picture and scored 2 points. Two participants (P7, female, 46 and P13, male, 40) provided answers worth 1 point. Three participants did not know what the picture represented when shown a drawing of a pregnant woman. Participant 19 (male, 35) said: "she's got fat belly" and Participant 20 (male, 52) responded "lady," which meant that they both scored 0 points.

The next question- “How does a woman get pregnant?” required the following response in order to be awarded 2 points: “sperm fertilises the egg after sexual intercourse/ through unprotected sexual intercourse.” An answer was worth 1 point if it included: “sexual intercourse, man puts his penis in the vagina, sperm in the vagina.”

Four participants (P4, P12, P19, P23) who did not know what pregnancy was and did not describe the picture correctly, were not asked the rest of the questions from the sub-section. Twenty participants (74%) knew how a woman got pregnant (eight participants gave answers worth 2 points and 12 scored 1 point). One participant (P20, male 52) said that he did not know and P14 (male, 58) said: “you get fat like that, her belly gets bigger” in response to the question.

The answer to the next question- “Can you have sex without the woman getting pregnant?” was a yes/no type, with the answer “yes” scored 2 points and “no” 0 points. Fourteen participants knew the correct answer to the question and scored 2 points, four people were not asked the question, one participant did not wish to answer the question (P13, male, 40), four participants said that they did not know and four replied “no.”

The next question was: “How do you stop the woman getting pregnant?” Participants needed to know that: “use contraception/ use a condom, the pill (other contraceptive device described)/ withdrawal method” was necessary in order to gain 2 points. If “use protection” was mentioned, 1 point was given. Answers such as “not to have sex/ anal sex” were not included in the scoring manual, but should be awarded in my opinion as they showed awareness of needing to have unprotected vaginal sex in order for a woman to become pregnant.

Eleven participants achieved 2 points. Four participants were not asked the question and seven responded “don’t know.” Participant 14 (male, 58) replied: “women get belly like that” when asked the question and Participant 26 (male, 61) believed that woman got pregnant every time people had sex and that “it would be very strange if it wasn't [true].” Both participants were given 0 points. Further two participants (P3, female, 24 and P9, female, 54) said: “not to have sex” and P5 (male, 50) responded: “not to do it with a man. A man put their penis into the ladies’ back end of the arse”, which as mentioned above, should be classified as them being aware of how to avoid pregnancy.

The answer to the next question- “Does the woman still get her period if she is pregnant?” was a yes/no type, with the answer “no” being worth 2 points and “yes” 0 points. Only five participants knew that a woman did not have periods if she was pregnant. However, with no follow-up questions, it could be a good guess rather than actual knowledge. Four participants were not asked the question and the rest (18) responded “don’t know” or “yes.”

The next question in the sub-section was: “Can a woman have a baby without getting pregnant?” with the yes/no choice of answers. Two points were awarded for the “no” answer and when participants mentioned “if she adopts/ fosters/ IVF (shows knowledge that she cannot have a child grow inside her without getting pregnant).”

Twelve participants knew that women could not have a baby without being pregnant unless adopted or fostered. Eleven participants replied “don’t know” or “yes” (four participants not asked).

The following question asked about the length of a pregnancy: “How long is a pregnancy? / How long does the baby stay inside the mother?” An answer “9 months (term)/ 40 weeks” was awarded 2 points, “full term/ between 6-12 months stated” resulted in 1 point given and an answer “a long time/ incorrect response (any length of time less than 6 months or more than 12 months)/ don’t know” was scored 0 points.

Eight participants stated that they did not know and four were not asked the question. Participant 5 (male, 50) replied “3-4 months”, Participant 8 (male, 38) said “12 weeks”, Participant 14 (male, 58) responded “1 week” and Participant 17 (female, 35) thought it lasted “28 days”. Further four participants believed that pregnancy was between 6-12 months (scored 1 point) and seven knew the correct answer to the question (“9 months”).

The next three questions were regarding childbirth. A correct answer, scored 2 points to a question “How is a baby born?” needed to include “out of the vagina or caesarean section.” If participants stated “out ‘down there”’, 1 point was given and “don’t know/ incorrect answer” resulted in 0 points.

Ten participants were aware that a baby was born out of the vagina or caesarean section and were given 2 points. Participant 3 (female, 24) pointed towards her pelvis, Participant 16 (female, 25) said: “outside of your legs,” which resulted in 1 point awarded. Three participants

said “stomach.” Seven participants said that they did not know how it happened. One participant did not wish to answer the question (P21, female, 17) and four were not asked the question.

The next task required participants to correctly describe activity portrayed on a drawing with the prompt question being: “What is this a picture of? What is happening?.” If participants recognised the activity as “a woman giving birth/ having a baby,” they were given 2 points. An answer: “woman and baby (no mention of giving birth)” was awarded 1 point and “don’t know/ incorrect response/ having a smear test” resulted in 0 points.

Nineteen participants correctly identified the activity represented in the prompt picture and scored 2 points. Four participants stated that they did not know what was happening in the picture and four were not asked.

The next question- “Does the baby come out of the same hole as the blood when a woman has her period?” had a yes/no format. An answer “yes” was awarded 2 points and “no” 0 points. Eight participants responded correctly to the question, however, with the format of the answer being yes/no, it was impossible to ascertain whether it the correct answer was down to being knowledgeable or a guess.

In order to be awarded 2 points for the answer to the next question- “Can men get pregnant?,” participants had to reply “no.” Twenty-one participants knew the correct answer, four participants were not asked and two replied “don’t know” (P14, male, 58 and P20, male, 52).

The next question- “Do children get pregnant?” is not very clear in my opinion, which is discussed in more details in the critical reflection section (Chapter 3.5). It was a yes/no type of answer, with “yes” scored 2 points and “no” 0 points, however, 2 points were awarded for “no” if the respondent mentions the need to have started ovulating according to the scoring manual.

Eighteen participants answered the question correctly, four participants were not asked the question, one participant said “no” (P1, female, 14) and P16 (female, 25) believed that having children was possible from the age of 25 and three participants stated that they did not know the answer. Participant 10 (female, 42) was aware that being pregnant at a young age (pre-puberty) should not happen, however not due to physical unreadiness, but rather missing experience of schooling:

“I: Do children get pregnant?

P10: Not boys, girls can.

I: From what age do you think they can get pregnant?

P10: I don't know. One of my friends when I was at school, she got pregnant when she was 13.

I: Do you think girls could get pregnant when they're younger than 13?

P10: I don't think they should.

I: But can they?

P: Yeah, but I don't think that they should cause then they've lost their school experience, haven't they?”

The next question was: “What does a woman do if she gets pregnant and doesn’t want the baby?” An answer worth 2 points needed to include “has an abortion or termination.” If participants mentioned “gets rid of the baby/ gives the baby up for adoption,” they were awarded 1 point.

Nine participants were aware that if a woman got pregnant, but did not want the baby, she could have an abortion. Participant 27 (male, 20) replied that: “if she doesn't want the baby, she can ask nurses to look after the baby” and Participant 26 (male, 61) said that: “she gives it up for adoption,” which resulted in both of them awarded 1 point. Twelve participants said that they did not know the answer and four were not asked.

The last question in the sub-section was- “What is an abortion?” An answer worth 2 points required explaining the procedure using words: “natural or induced premature expulsion of the foetus/ a procedure to extract (get rid of) an unwanted foetus/ baby/ termination of pregnancy.” If participants replied: “get rid of the baby/ ‘kill’ the ‘child’/ foetus that’s inside you (displays knowledge of extraction of foetus)/ destroy cells,” 1 point was given.

None of the participants provided a detailed definition of abortion as per the model answer sheet, but ten participants knew that it meant “getting rid of/killing the baby” and scored

1 point. The remaining participants (17) stated that they did not know the answer or were not asked the question.

Sexually transmitted diseases. The subsection consists of 11 knowledge questions. If participants did not know the answer to the first two questions ("What is a sexually transmitted disease?" and "How many types of sexually transmitted disease have you heard of?"), we moved to the next sub-section. The first question asked for a definition of STD: "What is a sexually transmitted disease?" According to the model answer sheet, the answer worth 2 points was: "disease passed between partners during sexual contact, usually unprotected." If "AIDS (or the mention of another STD)/ a disease you catch during sex (no mention of unprotected)/ get it if a man doesn't wear a condom" were mentioned, then 1 point was given.

Only two participants (P6, female, 42 and P18, male, 23) provided a definition which scored 2 points (none of the participants in the study by O'Callaghan Murphy, 2002). Five participants mentioned AIDS or HIV in response to the question, which was scored as 1 point. Two participants did not wish to answer questions regarding this topic (P23 and P26). Participant 27 (male, 20) responded: "diseases are very bad for health" and Participant 7 (female, 46) answered the question in the following way:

"I: What is sexually transmitted disease?

P7: STI.

I: STI. Do you know what it is?

P7: Sexually Transmitted Disease."

Sixteen participants stated that they did not know what sexually transmitted disease was.

Next, the participants were asked for the number of STDs known: "How many types of sexually transmitted disease have you heard of?" If at least two diseases, for example "Herpes/ AIDS/ HIV/ Chlamydia/ Venereal disease/ gonorrhea/ thrush/ syphilis/ crabs/ genital warts," were mentioned, 2 points were given. If participants only named one- 1 point was awarded.

Seven participants could name two or more STDs and five at least one (HIV and AIDS were mentioned the most frequently). Thirteen participants stated that they did not know any STDs (two participants did not wish to answer questions regarding this topic P23 and P26).

The next question: “How do you catch a sexually transmitted diseases?” was only asked if participants knew the answer to at least one of the above questions (13). If participants stated: “through unprotected sexual contact sexual acts that exchange bodily fluids (blood, semen)/ through having sex without using contraception,” they were given 2 points. If they were aware that it could be contracted “through sex/from someone else when you have sex,” without mentioning the lack of protection, 1 point was awarded. An answer: “don’t know/ incorrect responses/ kissing/ through dirty people” resulted in 0 points given.

Nine participants (out of 13 who were asked the question) were aware that STIs could be passed through sexual intercourse, with six of them knowing that it had to be unprotected (2 points). Participant 10 (female, 42) replied to the question in the following way: “if someone else has got something wrong with them you can catch it that way” and Participant 13 (male, 40) stated: “it's a virus. You can pass it.” The answers suggested some knowledge, but as they did not mention having sex, as required by the scoring manual, they were scored 0 points. Participant 7 (female, 46) replied: “I don’t know.” One participant (P24, female, 55) believed that STDs were results of lack of hygiene:

> “I: Do you know what sexually transmitted disease is?
>
> P24: You can get AIDS and also when the man don't wash, have a shower or bath, that's called...err...dirty. (…)
>
> I: How can they be passed from one person to another?
>
> P24: If one person have a shower or hair wash or bath, they're clean and the other one don't, you don't sleep in the same bed as him, so you don't catch it that way.”

The next question: “How can you tell if you have a sexually transmitted disease?” required the following response in order to be awarded 2 points: “through physical symptoms; sores/ warts/ discharge/ pain in genitals/ not always visible, but can have a blood test.” An answer “in pain/ visit doctor” resulted in 1 point given.

Five participants stated that a doctor must be visited in order to have a test/ check and four mentioned physical symptoms, such as pain or discharge. Four participants stated that they did not know the answer.

The next question- “Should you tell anyone if you think you have a sexually transmitted disease or not?” was a yes/no type, with the answer “yes” worth 2 points. Twelve participants responded “yes” and Participant 7 (female, 46) said that she did not know the answer.

Next, participants were asked: “Who should you tell?” with the answer “GP/ doctor/parent/ carer” worth 2 points and “friend” 1 point. Twelve participants (out of thirteen) scored 2 points. Surprisingly, an answer “partner/ people you had a sexual contact with” was not included in the model answer sheet, but most participants were aware that you should inform them.

Participants could score 2 points if they responded to the question: “Should you have sexual intercourse if you think you have a sexually transmitted disease?” “’No’, as you can pass it on or ‘yes’, if you use contraceptive protection and inform your partner.” An answer “yes, if you like; no mention of contraception)/ don’t know” was awarded 0 points. Nearly all participants who were asked the question (12 out of 13) knew that you should not have sexual intercourse if you thought you had STD. Participant 7 (female, 46) replied: “I don’t know.”

Next question was: “What is AIDS? What actually is it?” An answer worth 2 points needed to include: “Acquired immune deficiency syndrome/ a disease that attacks the immune system (progressive disease that comes from HIV).” If participants stated: “disease/ HIV/ an STD/ a virus that kills/ describes symptoms,” they were awarded 1 point and “don’t know/ germs/ something bad” 0 points.

One participant (P18, male, 23) knew that: “you can have HIV and then it turns into AIDS” (2 points) and six participants, who mentioned HIV or virus, were given 1 point for their answers. Participant 7 (female, 46) believed that HIV was “Hepsis something” and Participant 17 (female, 35) thought that AIDS was a form of cancer. Four people said that they did not know what AIDS was.

In order to achieve 2 points for the answer to the next question: “What happens to you if you get AIDS?” participants had to state that: “it attacks your immune system, and you get ill and may die/ immune system weakens.” If participants mentioned: “you die/ you can’t have unprotected sex,” they were awarded 1 point. An answer: “don’t know/ you get better/ take tablets/ incorrect response” resulted in 0 points.

Seven participants knew you could die from AIDS (1 point), but nobody could explain what happened to people when they had AIDS. Six participants responded that they did not the answer to this question.

Next, participants were asked: “What is the best way to stop getting AIDS?” If they mentioned: “use contraceptive protection/ use a condom/ rubber sheath,” 2 points were given. An answer: “protect yourself (no mention of how)/ not using needles” resulted in 1 point.

Five participants provided answers worth 2 points and three participants (P17, female, 35, P18, male, 23 and P25, male, 61) replied: “use protection” and scored 1 point. Participant 25 (male, 61) also added: “sex workers or people who are on the streets, not picking.” The rest of the participants (5) responded: “don’t know.”

Two participants (P7 and P13) mentioned a character from EastEnders who had HIV when discussing HIV and STIs. Participant 13 (male, 40) based his knowledge regarding HIV on the information seen in the TV series:

“P13: Do you know EastEnders? Mark had HIV.

I: I don't watch EastEnders. How do you catch sexually transmitted diseases?

P13: AIDS comes from HIV.

I: Good. How do you catch it?

P13: It's a virus. You can pass it.

I: How?

P13: Mark’s first girlfriend had an HIV and she passed it to him.

I: How?

P13: He had it. He had HIV and he died, cause he was not taking drugs. You can die from HIV.

I: How would you tell if you had it?

P13: He had a GP appointment and the GP told him.

I: And how did the GP know?

P13: The GP told him."

The information held by him was correct. Presenting information on issues such as HIV in TV programs can be used as a potential way of educating people, who might have restricted access to formal education.

Masturbation. There are three knowledge questions in the sub-section- "What is masturbation?" and two sets of drawings representing a man and a woman masturbating. Participant 11 (female, 51) did not wish to answer questions from the section and Participant 13 (male, 40) gave a definition of masturbation but did not wish to discuss it further. In one case (P27), questions from the section were not asked due to the fact that the mother of the participant was present in the room next door, so it was felt that it would be too embarrassing for the participant to discuss it. According to the model answer sheet, an answer worth 2 points to the question: "What is masturbation?" required the following definition: "produce sexual arousal by manual stimulation of genitals/ touching oneself for sexual stimulation or arousal/ touching oneself for sexual excitements." If "wanking/ touching self/ giving pleasure to self/ 'fingering' (other terminology used to refer to stimulation of genitals)" were mentioned, 1 point was given.

Two participants (P6 and P18) provided answers worth 2 points. Further four participants scored 1 point- Participant 13 (male, 40) stated: "it's private. I am playing with my penis in bed," Participant 17 (female, 35) replied: "It's when you touch yourself," Participant 22 (male, 55) said: "Touching. That's when you have an erection and stuff," and Participant 25 (male, 61) responded: "it's relieving oneself or another person." Participant 10 (female, 42) believed that masturbation was "blowjobs" and only men could do it (0 points). The majority of participants stated that they did not know what masturbation was (18 participants).

The next task required participants to correctly recognise activity portrayed on the two drawings- a man and a woman touching upper parts of their bodies. The prompt questions were: "What are these pictures of? What are they doing?" An answer: "masturbating/ playing with themselves (sexually)/ sexually arousing themselves" was awarded 2 points and "playing with self (no mention of sexual nature)/ touching breasts/ chest"- 1 point.

Three participants correctly described the two pictures and scored 2 points. Five participants stated that the pictures represented people "playing with self or touching their bodies" and were awarded 1 point. Ten participants said that they did not know what the drawings represented. Participant 1 (female, 14) believed that figures in the pictures were sleeping. Four participants believed that the picture of a man and a woman touching their bodies was about breast examination. Participant 24 (female, 55) not only believed that the activity portrayed in the picture was regarding health checks but also admitted that she would never do it in front of her husband.

The next two drawings represented a man and woman touching their genitals. If the participant "recognises both images as masturbating ('wanking')", 2 points were given and if "recognises one image as masturbating/ playing with him or herself/ fiddling with self"- 1 point was given. Only eight participants, who knew what masturbation was and correctly identified activity on the previous drawings, were shown the second set of pictures. All eight participants correctly described the drawings, with five participants scoring 2 points and three- 1 point.

***Homosexuality*.** There is one knowledge question in the subsection- "What is homosexuality?" An answer worth 2 points needed to include: "same-sex relationship/ a sexual relationship between 2 men or 2 women/ a gay or lesbian relationship." One point was given if the participant: "refers only to gay men having a sexual relationship or only to two women having a sexual relationship."

Seven participants had a good knowledge of what homosexuality was and scored 2 points. Three participants were given 1 point- two participants (P26, male, 61 and P27, male, 20) believed that homosexuality was two gay men and P25 (male, 61) appeared to confuse homosexuality and transsexuality: "It's two females, when they behave like man and female, but they're females, they have sex. They can go ahead and have realign, basically drugs to enhance testosterone or "e" word... err... oestrogen." One person did not wish to answer questions regarding the topic (P23) and 16 participants responded that they did not know what homosexuality meant.

The results regarding knowledge of homosexuality appear to be low but are higher than those reported by O'Callaghan and Murphy (2002) who found that only eight participants with

LD from their sample of 60 held correct knowledge about same-sex relationships and 75% did not know what homosexuality was.

3.4.3 The best and least known areas.

The SexKen subscales, the number of knowledge questions in each of them, the maximum and mean scores are presented in Table 10. In addition, a comparison of results achieved by participants in the sample to results achieved by the participants in the study by McCabe (1999) was made. McCabe (1999) interviewed sixty people with mild intellectual disability (28 males, 32 females, mean age= 27.62 years) in Australia using the SexKen scale.

For the purpose of the assessment of the best and least known areas, it was decided that if the percentage of the mean to maximum score was less or equal 33%, the knowledge would be described as poor, percentage higher than 33%, but lower than 66% suggests medium awareness and equal to or higher than 66% good understanding. Three questions in the Menstruation section were aimed at females only. For the ease of the comparison, they were removed leaving it with a maximum of 16 points (original max score 22).

Table 10

SexKen subscales, number of knowledge questions, maximum and average scores achieved by participants in the sample and comparison with those from a study by McCabe (1999)

Subscale	Number of knowledge questions	Mean score achieved by the participants	Maximum score possible	Percentage of correct answers	Mean achieved in previous research
Friendship	1	0.70	2	35%	0.80
Dating and intimacy	2	1.4	4	35%	1.48
Marriage	2	3	4	75%	2.56
Body part identification	21	34	42	81%	29.74
Sex and sex education	1	0.40	2	20%	0.51
Menstruation	11	6.1	16 (22)	40%	7.86
Sexual interaction	21	23	42	55%	18.94
Contraception	9	7.60	18	42%	6.28
Pregnancy, abortion, and childbirth	15	13.5	30	45%	10.86
Sexually transmitted diseases	11	6.30	22	30%	6.34
Masturbation	3	1.2	6	20%	2.22
Homosexuality	1	0.60	2	30%	0.63

The only two topics where the knowledge can be described as good are marriage and body parts identification. Participants possessed the least knowledge about homosexuality, masturbation, sexually transmitted diseases and sex.

The results achieved by the participants in my sample are very similar to those achieved by the participants in the study by McCabe (1999) except for the sexual interaction section where the mean in my sample was higher than in McCabe's (23 compared to 18.94), pregnancy (my study 13.5, McCabe's- 10.86), and masturbation (1.2 in my sample compared to 2.22 in McCabe's).

3.4.4 Experiences and needs.

Questions regarding people's experiences and needs formed part of the SexKen questionnaire. Content analysis was conducted in order to quantify the responses. Content analysis is a method used to analyse qualitative data. It allows us to transform qualitative data into quantitative data (Wilson & Maclean, 2011). As the participants had very diverse living arrangements, varying access to social activities and were people of different ages, their experiences are heterogenous, which affects generalisation of the findings.

3.4.4.1 Relationships.

All participants reported having friends; however, most people were only having contact with their friends at the day centres or groups they attended. Seven participants mentioned staff members and other professionals, including myself, as their friends and one participant (P12, female, 39) said that her only friend, apart from parents, was a befriender.

When it came to a boyfriend/girlfriend type of relationship, nearly all participants (25 people, 92%) had been in a relationship, either at the time of the interview or in the past. The information was gathered by asking several questions: "Do you have a special boyfriend, girlfriend or partner?" with a follow up questions concerning time together, frequency of seeing each other etc., "When was the last time you had a boyfriend/girlfriend, partner?," "Have you ever been in love or loved someone?," "Have you ever been married?" Participants' experiences about friendship and romantic relationships, as well as sexual experiences, are summarised in Table 9. One participant was married (P24, female, 55). Two of the participants were engaged with each other (P7, female, 46 and P8, male, 38).

Two participants (P18, male, 23 and P21, female, 17) described themselves as being homosexual and one person said that "she used to be a lesbian." Negative attitudes towards homosexuality, mentioned frequently by the teachers in Study 3, were not noted in this sample except for a situation when P15 (female, 23) stated that she "hated it":

"I: 'Is it ok to ask you some questions on homosexuality?

P: What the hell is that?

I: It's when people feel attracted to people of the same sex...so if women are attracted or fall in love with other women or men like other men.

P: Yuck! Hate that!

I: One of the questions is how you would feel about engaging in this kind of behaviour...

P: Hate it!"

In the report by O'Callaghan and Murphy (2002), 60% of participants with LD had a boyfriend/girlfriend/partner/spouse. Of these, only one male (out of a total sample of 60) identified himself as being in the same-sex relationship. Four people with LD were married and a further two men were living independently with a partner (O'Callaghan & Murphy, 2002).

3.4.4.2 Sexual experiences

The participants' sexual and relationship experiences are summarised in Table 11. Sixteen participants (60%) had been on a date compared to 92% of participants in the study conducted by O'Callaghan and Murphy (2002). Participant 14 (male, 58) said that he never went on a date as "I can't go downtown myself, I have to go with staff."

Twenty-three individuals (P23, female, 45 did not wish to answer any questions regarding her sexual experiences) reported having experiences of hugging other people; however, the question was unclear whether it was limited to romantic relationships only or could include hugging, for example, of family members. When it comes to cuddling with no clothes on, half of the participants (14) reported having such an experience. Seventy percent of the interviewees (19) gave an account of having experiences of kissing and 10 people had had sexual intercourse. It can be assumed that those questions were correctly understood by the participants

as all or nearly all correctly recognised the activities on drawings (hugging with and without clothes and kissing) and the majority (19) correctly identified sexual intercourse on the prompt drawing. More women than men (seven and three respectively) in the sample had had sexual experiences, however, more women took part in the study (16 vs 11 men).

When it comes to masturbation, the majority of participants did not know what it was or did not wish to answer the question regarding the topic (18 participants). In one case (P27), questions from the section were not asked due to the fact that the mother of the participant was present in the room next door, so it was felt that it would be too embarrassing for the participant to discuss it. Out of the nine participants who knew what masturbation was or did not mind talking about it, three individuals admitted to masturbating in private. Three people expressed a rather negative attitude towards masturbation. Participant 22 (male, 55) and P15 (female, 23) stated that they would never do it and P25 (male, 61) said that it was: "not ok [to do it] on the religious ground."

No questions were asked about experiences of abuse, but three participants disclosed that they had been victims of abuse in the past. One interviewee was assaulted when he was 11 (61 at the time of the interview). Another female was a victim of domestic violence. The perpetrator, who was her ex-husband, passed away a number of years ago. As both incidents were historical, no immediate action was taken. I informed facilitators of the advocacy groups, which the participants attended about the disclosure by emails after the interviews, as outlined in the safeguarding procedure. The third participant, who happened to take part in the research in the presence of a staff member, disclosed being sexually harassed in the past. The research's safeguarding protocol was to pass the information about potential abuse to a member of staff. The support worker witnessed the disclosure, but an email informing of the disclosure was also sent to the key worker.

Table 11

Participants' sexual and relational experiences

Participant	Friends	Relationship	Dating	Kissing	Hugging clothes on	Hugging no clothes	Sexual intercourse	Masturbation
1	Yes	No	No	No	Yes	No	No	Unknown (DK)[a]
2	Yes	Yes	No	Yes	Yes	No	No	No
3	Yes	Yes	Yes	No	Yes	No	No	Unknown (DK)[a]
4	Yes	Yes	Yes	No	No	No	No	Unknown (DK)[a]
5	Yes	Yes	No	Yes	Yes	No	No	Unknown (DK)[a]
6	Yes	Yes	Yes	Yes	Yes	Yes	Yes	No
7	Yes	Yes	Yes	Yes	Yes	Yes	No	Unknown (DK)[a]
8	Yes	Yes	Yes	Yes	Yes	Yes	No	No
9	Yes	Yes	Yes	Yes	Yes	Yes	No	Unknown (DK)[a]
10	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Unknown (DK)[a]
11	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Unknown (DW)[a]
12	Yes	No	No	No	No	No	No	Unknown (DK)[a]
13	Yes	Yes	No	No	Yes	No	No	Yes
14	Yes	Yes	No	Yes	Yes	No	No	Unknown (DK)[a]
15	Yes	Yes	Yes	Yes	Yes	Yes	Yes	No
16	Yes	Yes	No	No	Yes	No	No	Unknown (DK)[a]
17	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
18	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
19	Yes	Yes	No	Yes	Yes	Yes	Yes	Unknown (DK)[a]
20	Yes	Yes	No	Yes	Yes	No	No	Unknown (DK)[a]
21	Yes	Yes	No	Yes	Yes	Yes	Yes	Unknown (DK)[a]
22	Yes	Yes	Yes	No	Yes	No	No	No
23	Yes	Yes	No	Unknown	Unknown	Unknown	Unknown	Unknown (DW)[a]
24	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Unknown (DK)[a]
25	Yes	Yes	Yes	Yes	Yes	Yes	Yes	No
26	Yes	Yes	Yes	Yes	Yes	Yes	No	Unknown (DK)[a]
27	Yes	Yes	Yes	Yes	No	No	No	Unknown (DA)[a]
Total	**27 yes**	**25 yes**	**16 yes**	**19 yes**	**23 yes**	**14 yes**	**10 yes**	**3 yes**

[a] Unknown due to the fact that the participant did not know what it was (DK), did not wish to answer (DW) or the question was not asked (DA)

3.4.4.3 Contraception.

More than half of the participants (55%) in the sample had some knowledge regarding contraception but only 10 people (one refusal-P23) had experience of using some form of contraception (3 people had used condoms, 2 people both condom and contraceptive pills, 3 people had taken the pill and 2 females had had implants).

3.4.4.4 Sex education.

Thirteen people (48% of participants) reported having had sex and relationships education at school and three people were provided with some information on sexual health by their families (P15 said that her sister and dad had provided her with some information, P24 reported her sister as a source of knowledge and P21 knew about sexual health matters from her mum). Eight participants stated that they would like to have more training and information.

3.4.4.5 Needs.

Firstly, it is worth noting that the term "needs" is being used here as that was the word used in the Sex-Ken questionnaire. The term "desires" or "wishes" would be more appropriate, but to ensure consistency, the decision was made not to employ it.

Nearly 60% of participants (16) stated that they would like to have more friends and spend more time with them. Twenty- four participants reported that they would like to be in a relationship (P1, female, aged 14 replied "maybe"). Seventy percent of the participants (19 people) stated that they would like to get married; six individuals responded "maybe" and two said that they did not wish to have a wife/husband in the future.

Six participants (22%) affirmed that they would like to have children. None of the participants had children. Women were asked if they had been pregnant (part of the Pregnancy sub-section of the SexKen; P15- aged 23, reported having a miscarriage), but

males were not questioned about it and it was not mentioned in any of the interviews. Table 12 summarises the needs of people when it comes to relationships and parenthood.

Table 12

Summary of participant's wishes in respect of relationships and parenthood

Participant	Would like to have more friends	Would like to be in a relationship	Would like to get married	Would like to have children
1	Yes	Unsure	Yes	Yes
2	Unsure	Yes	Yes	No
3	Yes	Yes	Yes	Yes
4	Yes	Yes	Yes	No
5	Yes	Yes	Yes	No
6	Yes	Yes	Yes	No
7	Yes	Yes	Yes	No
8	No	Yes	Yes	No
9	No	Yes	Yes	No
10	Yes	Yes	Unsure	Unsure
11	No	Yes	Yes	No
12	No	No	No	Unknown
13	Yes	Yes	No	No
14	Yes	Yes	Yes	No
15	No	Yes	Yes	Yes
16	Yes	Yes	Yes	Yes
17	No	No	Unsure	Unsure
18	No	Yes	Unsure	No
19	Yes	Yes	Unsure	Unknown
20	Yes	Yes	Yes	Unknown
21	Yes	Yes	Yes	No
22	No	Yes	Yes	Yes
23	Yes	Yes	Yes	Unknown
24	Yes	Yes	Yes	No
25	Yes	Yes	Yes	Unsure
26	No	Yes	Maybe	Unknown
27	No	Yes	Maybe	Yes
Total	**16 yes**	**24 yes**	**19 yes**	**6 yes**

3.4.4.6 *Privacy.*

The questions in the SexKen regarding this aspect enquired about privacy in general. However, some participants spontaneously mentioned activities, such as inviting partners to their home, when talking about privacy. In addition, in situations when people did not understand the word "privacy," I would give an example of having sexual intercourse. Only one participant from the sample (P27, male, 20 who was living in a flat with his mum) said that he would not have enough privacy if he wanted to invite girlfriend home. Another participant (P16, female, 25) replied that she would have enough privacy, but if she wanted to have sexual intercourse, her parents would probably tell her that she needed to get married first. Most participants (26) reported having enough privacy where they lived.

Participant 5 (male, 50) stated that if he wanted to go on a date or invite somebody to his bedsit, he would need to do it without the staff's knowledge. It would appear that it was his decision rather than policy, but such behaviour might be due to staffs' attitudes. That was the only instance when a participant mentioned restrictions to being in a relationship imposed by service providers or families, something which was frequently mentioned by participants in previous studies (e.g. Whittle & Butler, 2018). In fact, apart from the support provider mentioned by Participant 5, remaining providers appeared to be supportive and helping people to be in a relationship. Information about attitudes of support staff was not gathered as a part of the questionnaire, but spontaneously mentioned by some of the participants. Participant 10 (female, 42) reported that where she lived, married couples could share bedrooms and single people, who wanted to invite partners to stay, could join beds. Participant 15 (female, 23) said that when she invited somebody to her bedsit for the first time, staff would check on her, which she appreciated. After getting to know the person better, knowing she was safe and comfortable, staff would let her enjoy her privacy.

3.5 Critical Reflections

3.5.1 Conducting the interviews.

To increase the participation of people with LD in the research, all efforts need to be taken to make it as accessible and non-problematic for the individuals as possible. However, this means that the circumstances or the environment where the interviews are conducted can be very different from those found in the universities or dedicated interview/ consultation rooms. Conducting research, for example, in people's homes or other places familiar to them, could make individuals more comfortable and at ease. In the research by Ecker (2017), interviews conducted in the community were rated more positively by the participants than those conducted at the research centre. Yet, there are some disadvantages as well. One of them is the lack of control the researcher has over external factors such as other people being around or the physical restrictions of the place; for example, the room not being appropriate or comfortable enough to carry out interviews. Interviews in private residences can also pose a safety risk to the researchers. Such challenges regarding my research are discussed below, as well as issues associated with the topic of the study.

Longhurst (2003) suggested that interviews need to be conducted somewhere "neutral, informal and easily accessible," (p. 110) but the main criteria for selecting a place should be that the interviewees feel comfortable. I believe that all the locations where the interviews for the study took place fulfilled the criteria of accessibility and familiarity as they were participants' homes or day/community centres attended on regular basis and had no physical barriers. Most participants appeared to feel at ease during the interviews, which is discussed in more detail below. The neutrality criterion was not always met. Interviews, which took place in the services, required permission from the manager. Participants could then perceive me as a staff member or authority figure. Potentially, they could also have concerns about me passing information on to the manager, despite my reassurance that

everything they said would be confidential. In fact, one of the participants asked me if I was going to tell the manager about his friends.

In the study, potential participants were offered the choice to have the interviews conducted at a place and time convenient for them. Overall, the interviews took place in three types of locations: people's homes (eight in total: two of them being residential services, four people lived with their parents, and two interviewees lived on their own), in day centres attended by the participants (eleven interviews) and in a community centre where people were having advocacy group meetings (eight). At the last location, a consultation room had to be hired, which posed some issues. The room was small with stud partition walls, which meant that potentially the conversation could have been heard outside of the room. After one of the interviews, conducted with an individual with a very loud voice, the receptionist asked us to keep voices down, as in the room next to the one we were using hearing tests were taking place. Another participant interviewed in this room was overweight and struggled to sit comfortably on the chair available. The room did not meet the criterion of physical comfort but was a well-known place to the participants, which did not cause any distress that could have been associated with visiting new, unfamiliar places. The interviews took place at different times of day, convenient to the participants.

During three interviews, which took place in family homes, the parents were present in the rooms next door. It was impossible to establish how much carers could overhear and what impact this could have on the honesty of the answers. None of the participants verbalised any concerns about this and did not appear to be uneasy because of it. In one case (Participant 27), the mother went out, but returned home before the interview was completed, hence some of the questions were not asked (section on masturbation) as it was decided that it would be too embarrassing for the participant to answer them.

During two interviews, staff members were present. In one instance, the presence was requested by the participant in case she became upset. On the second occasion, it was

suggested by the staff member to ensure my safety and to aid communication. During the interview, when the participant herself requested the presence of the staff, the support worker sat quietly in the room and did not intervene or add anything to the interview. The participant seemed to be very open and honest when answering the questions and generally appeared to have a very good relationship with her key worker. During the interview, I asked the participant several times if she wanted the staff member to be present and the interviewee replied that "when she's [staff member] concentrating, she is not really listening. But then I have confidence when she's there when I get upset with something." She also told me that she openly spoke to female staff members about sex-related issues.

In the second case, the staff member assisted with the communication as the participant presented limited verbal ability and his speech was slurred. The interviewee also turned several times to the staff member for reassurance. Overall, the staff's presence was helpful, but when the participant admitted to having an experience of intimate kissing with his girlfriend, the staff member (S) appeared to be surprised.

I: Have you ever kissed anyone?

P20: Used to.

I: You used to? Not anymore?

S: Normally it's just on the cheek, isn't it? And a cuddle.

P20: Cheek. [name of the girlfriend] and snog.

S: You give [name of the girlfriend] a snog?!

P20: Yes.

S: You do give her a snog?!

P20: Yes [laughs]

I reassured the participant that it was ok to do it, in case he thought he had done something wrong. However, the staff's reaction could have meant that potentially he did not want to admit to other experiences if he had had any.

The majority of the interviews, especially those conducted in the day centres and in the community hub had time restrictions. People attended the day centres between the hours of 10 am and 3 pm, with a lunch break between 12noon and 1 pm. That meant that the interviews had to be finished before closing time and start no earlier than 10 am as this would interfere with the transport arrangements. In addition, care was taken not to disturb people's routine i.e. not to be late for lunch. Hiring the room at the community centre meant that it had to be vacated by an agreed time. This had a negative impact on the number of prompt/clarification questions asked, meaning that in different conditions I may have probed further.

Overall, I did not feel too embarrassed about asking the questions but felt the most uneasy when interviewing a young man. I believe that this was due to the fact that he appeared to be very embarrassed, however, when I asked him a question (part of the questionnaire) whether he thought it was embarrassing to talk about sex, he said "no". I found it easier to conduct interviews with females and with the older participants. The most difficult set of questions was regarding masturbation, as I felt this topic was the most private. This could have been picked up by the participants and explain the large number of participants not wishing to discuss the topic.

On a few occasions, participants asked me personal questions in relation to the questions I was asking them. Several people asked me if I was married or in a relationship and one person (P14) asked me if I ever had sex, after I asked him about his sexual experiences. I replied honestly to all questions. I was also asked a number of times to explain or define terms to the participants when they were not familiar with them. For example, P8 stated that he never heard of menstruation or periods and asked me what it was. In all cases, I

attempted to answer to the best of my knowledge. I did not score or ask subsequent related questions in these situations. The only instance when I would not ask some questions was when participants clearly had no knowledge regarding the topic and when, as described above, a mother of the participant was in the room next door and the section on masturbation was omitted.

Another difficulty when conducting the interviews, was the fact that English is not my first language, and because of that I am not familiar with colloquial terms used to describe, for example, sexual organs and was not able to replace some of the formal, medical terminology used in the questionnaire, to make it easier to understand for participants, especially for private body parts. An example of this was, when during one of the interviews conducted with the staff member being present, I asked the participant to point to the vagina in the prompt picture, and he did not appear to know the answer. The staff member suggested that I used another word. The only one that I could recall was "pussy," which led to both the participant and staff member laughing. The staff member proposed the word "minnie," which the interviewee was familiar with.

A further factor, which had an impact on participation, was the cash payment as gratitude for the time the interviewee had given to the study. Recruitment rates increased significantly after the introduction of the monetary incentive (from two participants to 27 within eight months, however some other changes to inclusion criteria were made as well). I did not ask the participants what their motives for taking part in the study were, but the number of people who agreed to take part would suggest that payments were an important factor. Similar observations were made by Head (2009). An example of such a motivation was a situation that I encountered where one of the participants became very upset, as she believed that I would not be able to see her that day and she had already planned how to spend the money. Another participant, when asked at the end of the interview how did it feel, replied: "Fine. I want my money now." The payments caused some confusion as well. Two

people believed they needed to pay me for participation in the research, yet still agreed to take part.

It was mentioned by several gatekeepers that they liked the idea of me offering payments to people with LD as often they were excluded from research and/or not treated in the same way as non-disabled participants. When I expressed my astonishment that so many people wanted to take part in my research to the facilitator of the advocacy group, where I recruited a number of participants, she stated that relationships and sexuality were topics that the group members were rarely spoken to about, but were important parts of their lives.

Overall, my approach to interviewing the participants was very individual, for example rephrasing some of the questions or replacing terms, when participants did not seem to understand them, but demonstrated some knowledge and lack of embarrassment. This is in contrast with classical, especially quantitative, approaches to research, where it is advocated to have a standard approach to all respondents in a study. However, I agree with the recommendations of Gilbert (2004) that due to the range of different impairments experienced by people with LD, the interviewing requires different approaches for different individuals. I believe that especially because the topic of the study was sensitive and potentially difficult and upsetting for some people, a personal and considerate approach needed to be employed.

3.5.2 Participants' reactions during the interviews.

Overall, the majority of the participants did not seem to be embarrassed during the interviews. Participant 8 (male) admitted to feeling embarrassed:

"I: Do you think it is embarrassing to talk about sex?

P: Can I be honest with you? Yes.

I: Would you say it's very embarrassing, extremely embarrassing or just embarrassing?

P: Embarrassing, cause you really don't want to tell others what you do when you're on your own. You don't want to tell everybody what you've been up to."

One individual (P20, male) was laughing most of the time, which can be interpreted as a sign of embarrassment. Another person (P13, male) seemed disgusted by some of the pictures. When shown a picture of a naked kissing couple, he said:

"P: They are kissing! Eww!

I: Eww?

P: The ladies' tits are hanging off. Blee! I'm a little bit uncomfortable with that one."

One participant (P3, female), when shown a picture of a man masturbating and asked if she knew what he was doing said: "Holding it. That's embarrassing." Participant 22 (male) commented laughing that talking about sex was not embarrassing as if it was not for the sex, "none of us would be here." Another person (P5, male, 50) reported that he talked about sex-related issues to other service users, but not to the staff. He commented that he could not talk to the staff as it was a "workplace" and it was embarrassing.

As reported previously, to safeguard the interviewees and to make sure that no harm was caused, participants were frequently reminded that they did not have to answer the questions. Eight participants declined to answer single questions or whole sub-sections, which could have been due to them being too embarrassed or not having any knowledge of the area. One participant (23, female) replied "pass" to the majority of the questions and therefore scored the lowest of all. At the same time, several people stated that they were glad that they had decided to take part. Participant 11 (female) said: "I feel great about doing this!" Participant 1 (female) told her mum after the interview that she really enjoyed doing it and P20 (male) kept asking for more questions. Another participant said to me: "I like you (…) You are so kind." When I asked one interviewee (P21, female) if we could talk about one of the topics, she replied: "Anything for you, cause you're a lovely person."

Positive reactions during the interviews may suggest that the participants did not see me as another professional and the interviews being "merely a form of professional surveillance," which can be frequently observed in research involving people with LD (Booth & Booth, 1996, as cited in Gilbert, 2004). I attempted to create an atmosphere of openness and comfort by emphasising the practical outcomes of the research (guidelines and information for service providers and parents), as well as by being honest about my personal experiences. The fact that the interviews took part in the community and places familiar to the participants, but not to me, also helped to minimise the power imbalance, which can be present between researcher- responder. The interviews, which took place in people's homes, meant that I was in the position of a guest. This potentially resulted in participants feeling more in control and at ease, but may have served as a distraction to me and could have affected the way interviews were conducted, for example, fewer opportunities to probe for more detailed responses so as not to come over as an intrusive guest (Ecker, 2017).

3.5.3 The Sex-Ken questionnaire.

Overall, I was not satisfied with the Sex-Ken questionnaire and I found a few problems with it. First, some of the pictures are not clear. When shown a picture of people touching their bodies in the masturbation section, many participants thought it was about breast examination (see Figure 1), which was scored as incorrect. However, the results might be due to the low level of knowledge about masturbation, as in the study by Siebelink et al. (2006), only 51% of the participants noticed that the person on the drawing (created by the authors for the study) presented to them was masturbating. Clinicians interviewed by Thompson et al. (2016) regarding content, usefulness and usability of sexual knowledge assessment tools for people with LD (including Sex-Ken) also expressed concern that the pictures in the tools were sometimes confusing for people with LD, meaning that an accurate assessment result was difficult to achieve.

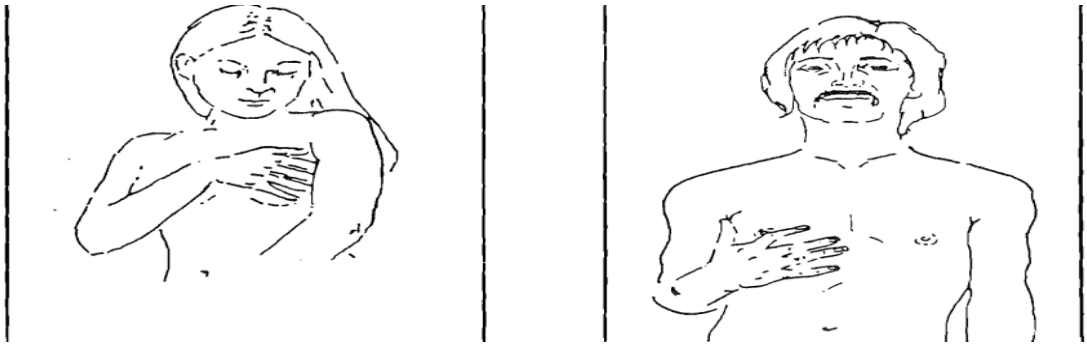

Figure 1. Prompt picture from the SexKen questionnaire, masturbation subscale, man and woman touching their bodies (SexKen-ID, McCabe et al., 1999)

Most pictorial prompts are line drawings, but the pictures of sanitary products and contraceptives are photos of very poor quality. I used some pictures downloaded from the internet and presented both- my image and the one provided by the SexKen each time. However, in general, I believe that the pictures were useful and more of them should be included. They served two purposes: as prompts when people were not sure about definitions of things such as marriage, or to confirm that people did not have knowledge in certain areas. In future developments of new tools, care needs to be taken to make sure that the pictures are clear and non-ambiguous. Clinicians from the Thompson et al. (2016) study also expressed concern that the sexual knowledge assessment tools did not contain enough pictures to enable them to determine whether people with LD did not possess knowledge in the area being assessed or whether they could simply not relate to the image being shown.

Some questions, in my opinion, are not well phrased. An example of such a question in the section on STIs is: “How many types of diseases have you heard of?” To some individuals, this might be too difficult, as it requires them to recall the information, count it and give a number. In addition, those people who answer the question can give a number and there are no follow-up questions to prompt them to give names of the diseases in order to check that they are actually aware of STIs. O’Callaghan and Murphy in their study (2002)

asked participants to list the diseases. The question can also be misleading, as it does not specify that it refers to sexually transmitted diseases.

Another example of a question, where there is no possibility to assess whether people actually hold the correct knowledge is: “When a woman has her period, does the blood come out of the same hole where the urine comes out?” with “yes” and “no” replies possible. There are no prompt questions following it and as a result, no way of checking if the answer given was due to being knowledgeable or a guess.

Certain questions can be seen as ambiguous or difficult to answer. An example of the question, which might be problematic to people with LD, who might find abstract thinking challenging, is “What is meant by feeling close to someone?” Some participants understood it literally, like a physical closeness, which might be alternative, however in the scoring manual used by me (created by A. O’Callaghan and Prof Murphy) it was seen as an unacceptable answer. Another example of an ambiguous question is- “Do children get pregnant?” People can have different definitions of when childhood ends. I was adding a follow up question, asking participants from what age it was possible to become pregnant, accepting onset of puberty (ages 10 to 15) as the cut-off point. In the version of the SexKen questionnaire used in the research by O’Callaghan and Murphy (2002), who adapted it, the question was rephrased to “Do children under the age of 10 get pregnant?” which is much clearer.

Some of the questions are long and as such difficult to comprehend. An example is: “Can you say 'no' to somebody who wants to kiss you or touch you?” On two occasions, I had to repeat the question. Easy read guidelines recommend that there should be three to five words in each sentence in order to make it easier to understand and remember for people with LD. In addition, in my opinion, to reduce the length of the questionnaire, only questions regarding private body parts should be kept in the body parts identification section.

One of the questions in the section regarding homosexuality can be seen as offensive to homosexual participants. When asked: “What made you decide this?” [that you are gay], one of the interviewees, who was gay became upset and replied: “I didn't decide it!” The question suggests that people decide whether they are homosexual or not, rather than it being part of who they are.

As mentioned previously, there is no manual or scoring sheet provided with the tool. As the authors of the scale are no longer in possession of them, I emailed some researchers who used the scale in the past. Professor Murphy kindly let me use a scoring manual created by her and O'Callaghan in 2002 for their study regarding capacity of people with LD to be in a relationship (G.H Murphy, personal communication, April 23, 2018). The scoring manual created by them is clear and easy to follow in my opinion. However, the lack of a standard manual used by all researchers creates problems with the reliability and validity of the tool. Not having clear rules regarding procedures and scoring means that different researchers might be applying the tool differently. Further issues with the scoring manual and suggestions regarding it, are provided in Chapter 3.5.5.

In addition, there are no instructions available and it is unclear whether it is acceptable to ask follow up questions or rephrase words used for ones that might be easier to understand to the participants. Some questions already consist of alternative terms (“What is contraception or birth control?”), but others do not (“What is a condom?”). I was inconsistent with rephrasing some of the terms, for example I was replacing the word females/ males with ladies/guys frequently, but other words such as “penis” infrequently, mainly due to lack of knowledge of an appropriate replacement.

The SexKen questionnaire is divided into three parts, each with multiple sub-sections, with examples of questions covered in the next part asked at the end of the antecedent part in order to determine if people possess sufficient knowledge to proceed. However, I did not find it useful or practical as each part consisted of sub-sections not linked to each other. For

example, part 2 includes questions on sex and sex education, menstruation, sexual interaction, and contraception. According to information provided by the authors of the scale, if people did not know the answer to the questions on a preceding section (not specified how many), the interview should not proceed to the next section: "The first interview includes knowledge questions relevant to the second interview. This procedure identifies whether responders have sufficient knowledge of these areas of sexuality to proceed with the second interview. Only those sub-sections for which there is an adequate level of understanding will be completed in the second" (McCabe, 1994, p.2). Nevertheless, I found it better to ask for consent at the beginning of each sub-section and decide whether to go ahead with it depending if people agreed and knew the answer to the first question, which is usually a question asking about the definition of the leading topic of each section and whether they could recognise the activity/item represented in the prompt picture. Authors of the questionnaire state that the subscales range from the least intrusive to the most; however, this is questionable as questions regarding sexual intercourse and sexual experiences, therefore enquiring about private information, are asked before questions regarding pregnancy or contraception, which in my opinion are less invasive.

Another difficulty that I found with the questionnaire being divided into three parts is the fact that the consent to proceed should be sought before each of the parts. That means that participants have to remember what topics will be covered and agree or not agree to take part in all of them. For example, in interview 3 participants are asked: "We want to ask you a number of questions about pregnancy, abortion and childbirth, sexually transmitted diseases, masturbation and homosexuality (…) Do you want to take part in the first bit of the study?". Instead, I found it easier to ask for consent before each subsection e.g., I would say what topic we would cover and ask for permission to ask questions on it.

Some aspects of sexual interactions are not covered by the Sex-Ken, for example foreplay and oral sex. O'Callaghan and Murphy (2002) added several questions to the

SexKen questionnaire, for example: “What is oral sex?” “What is foreplay?” “What is anal sex?” “Can women/girls get pregnant the first time that they have sex?”

On the positive side, the questionnaire is comprehensive and consists of questions regarding many areas of sexual health and relationships.

3.5.4 Revised version of the Sex-Ken and recommendations for the application.

Based on the issues identified in the critical analysis above, I have created a revised version of the SexKen, which can be found in Appendix 2. The revised version consists of initial suggestions and includes changes that I believe should be made. In order to be used in future research, the revised version would require validation.

As mentioned previously, as there is no manual available with the SexKen tool, it is unclear if prompt questions are allowed, whether it is possible to rephrase some of the words/ questions and if so, how it can be done. In the revised version of the tool, I clarify these ambiguities. The changes from the original version are highlighted.

I also provided suggestions for replacement terms in the situation when the participant is not familiar with the formal term, for example, the word “vagina” can be replaced with “front bottom/lady parts/ any other locally used words or informal terms.” It is impossible to list all the synonyms, as these will depend on the region, age of the participants and many other factors. Whenever possible, the terms used by the participants themselves should be employed. If feasible, it is advisable to check what words are familiar to the participant with the family or carers before conducting the interview.

Four additional questions added by O’Callaghan and Murphy (2002) to the SexKen questionnaire (“What is oral sex?” “What is foreplay?” “What is anal sex?” “Can women/girls get pregnant the first time that they have sex?”), are included in the revised version of the Sex-Ken questionnaire.

3.5.5 The model answer sheet- issues and recommendations.

Despite the fact that I found the scoring manual by O'Callaghan and Murphy (2002) very thorough and easy to follow, I believe that some of the model answers should allow for more options. Below, I outline the answers and questions, which based on the responses of the participants from my sample, were too demanding or had limited options. I also propose how issues could be improved. The new, updated scoring manual is attached as Appendix 4. As with the revised version of the SexKen, the updated model answer sheet consists of initial suggestions and would require validation.

The model answer by O'Callaghan and Murphy (2002) requires a sophisticated description of friendship. Some examples of "incorrect" answers given by the participants in my sample suggest that people were familiar with the term but did not use the descriptors from the scoring manual. In my opinion, the model answer should be simplified and statements suggesting the understanding of the relationship should be scored. I propose that the answer worth 2 points should include the following descriptors: "enjoying company/ spending time with somebody/ trusting/ knowing the person well/ getting on/ sharing interests/liking each other." A simpler description, suggesting an awareness of the relationship such as: "friends/ mates/ going out/ people you have known a long time," should be given 1 point.

A model answer to the question: "What is a date?" also required a sophisticated description. Once more, some of the answers, which were scored 0 points suggested that people were aware of the activity. Therefore, the acceptable answers should be more flexible and allow for responses, which imply an awareness of the activity, to be scored 1 point. In addition, in the existing model answer sheet, an answer being a specification of a place where one might go for a date can be scored 2 or 1 points. I suggest that a response mentioning a place or activity associated with dating should be awarded 2 points. An answer suggesting

knowledge of the activity, such as: “romantic/ kissing/ ask out/ go out/ any other statement or word suggesting awareness”’ should be awarded 1 point.

The question “What is meant by feeling close to someone?” and answer required by the model answer sheet proved to be difficult. In my opinion, an answer worth 1 point, as suggested by O’Callaghan and Murphy, should be awarded 2 points: “you like someone or trust confide in or feels nice to be with/ they’re important.” When participants mention physical closeness or examples of a behaviour suggesting closeness (physical and emotional) it should be accepted as correct and given 1 point, for example, kissing mentioned by the participants.

The body parts section asked participants to identify and name the functions of the body parts. However, the scoring manual only accepted sexual functions of mouth, penis and vagina, for example, the definition of mouth must “include kissing.” The suggested new scoring manual accepts any correct function of the body parts, for example “to wee (or any other words used to describe passing urine)” for penis and vagina, giving 1 point for correct identification and 2 points for recognition and any function of a body part.

Next, the question- “What is pregnancy? What does it mean to be pregnant?” required a very detailed answer according to the scoring manual by O’Callaghan and Murphy. In my opinion, an answer to this question should not require medical terms, such as fertilisation. A definition suggesting knowledge of “baby growing in the womb/ belly/ tummy, women expecting a baby” should be awarded 2 points. One word or simple explanations implying awareness, such as “9 months/ big belly/ baby” should be given 1 point.

When the “How do you stop the woman getting pregnant?” question was asked, the participants needed to state: “use contraception/ use condoms, the pill (other contraceptive device described)/ withdrawal method” in order to gain 2 points. If “use protection” was mentioned, 1 point was given. Two participants mentioned abstinence and one participant anal sex as a way of avoiding pregnancy. Such answers were not included in the scoring

manual, but should be awarded 1 point as, in my opinion, they showed awareness of needing to have unprotected vaginal sex in order for a woman to become pregnant. An answer "use protection/ any method of contraception" should be awarded 2 points, and not 1 as suggested by O'Callaghan and Murphy (2002). An answer worth 1 point should include the following: "not to have sex/ anal sex/ any other answer suggesting knowledge of not having vaginal sex without protection."

In response to the question "How is a baby born?" three participants responded "stomach." Such an answer was not included in the scoring manual but should be scored 1 point in my opinion as it suggested some awareness. Therefore, answers such as: "down there/ (out of) stomach/ belly/ tummy/ doctors cutting the tummy" should be accepted as they show awareness and should be scored 1 point.

The answer to the "What is an abortion?" question required using medical terminology. None of the participants provided a detailed definition of abortion as per the model answer sheet, but ten participants scored 1 point. I suggest that the answer "getting rid of/'killing' the baby/ termination of pregnancy" is sufficient and should be awarded 2 points. Answers such as: "miscarriage/ it's what you do when you don't want to have a baby," should be given 1 point.

The question: "Should you tell anyone if you think you have a sexually transmitted disease or not?" is followed by: "Who should you tell?" None of the options in the scoring manual mentioned sexual partners (current and past), which in my opinion should be added to the answer worth 2 points making it: 'GP / doctor/ parent/ carer/ partners (current and ex)'.

3.5.6 Limitations of the study.

Apart from issues outlined in the previous sections, such as problems with settings where the interviews were conducted or the questionnaire, there are several limitations of the study that affect the generalisations of the findings.

It has to be acknowledged that the broad age range of participants in the sample, means that the interviewees had very diverse life experiences and current circumstances, including, for example, different experiences of schooling, history of relationships or living arrangements. They also differed in terms of social exclusion, which was shown to have an effect of the level of knowledge (Pownall et al., 2017). It can be assumed that all of these factors affected participants knowledge and sexual/ relational experiences meaning that the findings have to be treated with caution and the generalisation of them can be hindered.

Secondly, there is a large amount of missing data when participants declined to answer some of the questions, or the questions were not asked due to other reasons. The missing data was replaced with the means of other scores, which is considered a good method of handling missing data, but it has its limitations as well. Mean imputation attenuates any correlations involving the variables that are imputed, which means that potentially some of existing relationships between variables were not detected. Overall, missing data can lead to invalid conclusions.

Having a pilot study would potentially highlight some of the issues with the questionnaire and the scoring system and other problems encountered during the research. Pilot study was not conducted due to two reasons. Firstly, as mentioned previously, recruitment was very difficult and having to recruit additional participants for the pilot study would be very problematic. Secondly, by making a decision to use a tool which was frequently used in previous research and had good statistical properties, the assumption was that it should be fit for the purpose and user friendly, both for the researcher and the participants. In addition, even if the issues with the questionnaire were detected during the pilot study, in order to test an amended version of it or another tool, one more pilot would need to take place.

Lastly, based on extensive literature highlighting difficulties with interviewing people with LD, such as ability to verbally express what they know, some steps were taken to fully

access their knowledge, but more could have been done. For example, a list of words which could be used as replacements of medicalised or formal terms used in the questionnaire, could have been prepared and used.

3.6 Discussion

The results of my study show that knowledge concerning sexual health and relationships is highly variable, from the very simplistic, limited mainly to knowledge of body parts, to full awareness of issues related to sex and sexuality. This could be related to the level of functioning of the individuals as the study demonstrated that there is a strong association between IQ levels and levels of knowledge about sex and relationships. This was shown in several previous studies (e.g. Konstantareas & Lunsky, 1997; Leutar & Mihokovic, 2007). However, some authors argued that it was not clear how much the better performance of people with milder impairments was due to better communication and how much to greater knowledge levels (Talbot & Langdon, 2006). This could be observed in my research when some participants clearly possessed knowledge on a certain topic, but were not familiar with the words used or could not articulate what they knew. For example, Participant 9 (female, 54) said that she did not know what contraception or birth control was, but earlier in the interview, informed me that she had an implant and knew it "was to protect her from having babies."

The better performance of people functioning at a higher level might also be due to better access to sex education, especially if they attend mainstream schools, where they have access to more extensive sex education. Participant 22 (male, 55) expressed an opinion that "ordinary school is better, because they explain things to you." He also stated that: "I think, personally, because we had like a special teacher and I don't think she went over it enough, really, cause you have all sorts of relationships, and not being disrespectful, I don't think they told us enough, but that's just my opinion." The relationship between schooling and higher levels of sexual and relationship knowledge is backed up by the fact that the participants in

my sample who reported having some form of sex education scored significantly higher on the SexKen questionnaire than those reporting no formal sex education. The association between taking part in sex education and improvements in knowledge was shown in previous research (e.g. Lindsay et al., 1992; Penny & Chataway, 1982).

The results of my study suggest that there is no association between age and knowledge and no difference in knowledge between males and females, which was also reported in previous studies (e.g. Galea et al., 2004; McGillivray, 1999; Ousley & Mesibov, 1991; Siebielink et al., 2006).

The study demonstrated that there is an association between sexual experiences and levels of knowledge about sex and relationships. The results suggest that the participants who had had sexual experiences were more knowledgeable than those who had not. In previous research, the association between sexual experiences and knowledge was not consistent. Ousley and Mesibov (1991) found no correlation between experience and the level of knowledge amongst people with developmental delay and autism, while Michie et al. (2006) found that sex offenders with intellectual disabilities had higher levels of knowledge than non-offenders. According to the authors, it could be assumed that sex offenders had some experience of sexual activity, which cannot be presumed with the control participants. The better knowledge of people who had had sexual experiences could be due to the fact that they had first hand experiences of, for example, opposite sex body parts. This claim can be supported by the fact that the only three participants in my sample, who could explain what was happening when both sexes have an orgasm, had had sexual experiences.

Participants in my sample appeared to have good knowledge of marriage and body parts identification and possessed the least amount of knowledge about homosexuality, masturbation, sexually transmitted diseases, and sex. The results correspond with the results of the literature review of the levels of knowledge of people with LD about sexual health conducted by myself (Borawska-Charko et al., 2016), which found that the topic of body

parts appeared to be the best known. The sexual health knowledge results achieved by the participants in my sample were very similar to those achieved by participants in the study by McCabe (1999). However, due to the limitations of the study, especially the extent of missing data, the results need to be treated with caution.

Nearly all the participants (25) in my study had had experience of having a girlfriend/boyfriend/ partner either at the time of the interview or in the past. Most participants with LD in the focus groups ran in two separate studies by Healy et al., (2009) and Kelly et al. (2009) had developed friendships and relationships with members of the same and opposite sex, and all expressed an interest in having such relationships, similar to the participants in my study. In addition, a review of qualitative studies investigating people with learning disabilities' views on relationships (Whittle & Butler, 2018) uncovered the same finding that the majority of papers reported that people with LD had a desire to be involved in an intimate relationship and expressed a wish for future marriage. The same review (Whittle & Butler, 2018) found that the majority of the respondents expressed the possibility of having children, whilst only 22% of the participants who took part in my study wanted to be parents.

Seventy percent of the participants in the study reported having experiences of intimate kissing and 38% of sexual intercourse. This is similar to findings from previous research. McCabe and Cummins (1996) found that 80% of the respondents with mild LD had experience of kissing and 48% of sexual intercourse. In the study by Siebelink et al. (2006) 76% of the participants had experiences of kissing and hugging and 45% of sexual intercourse. In contrast to previous studies (e.g. Hollomotz & Speakup Committee 2008; Rushbrooke et al., 2014), the participants in my sample did not report facing barriers or negative attitudes from support providers and families to their forming relationships and enjoying privacy.

One problematic area when working with individuals with LD on sex and relationship projects is their potential withdrawal due to embarrassment; however, the level of embarrassment of the people who took part in the study appeared to be low. Siebelink et al. (2006) also reported the lack of discomfort when taking part in sex-related research. In their study, however, they noticed differences between the reports of the interviewer and the observer regarding discomfort of the people taking part in the research. The observer was a staff member working with participants, who was present during the study and was given the task of noting signs of embarrassment. The observer reported higher levels of embarrassment in the people with LD than the researcher who was conducting the study. Siebelink et al. (2006) concluded that staff members knew the participants better and were only focused on the task of observation. Therefore, it is possible that the level of discomfort amongst the participants was higher than I noticed.

The use of self-report measures among people with LD is not without challenge. As Hartley and MacLean (2006) pointed out, self-report measures require that participants understand the questions, form responses and communicate them. Self-report measures also require long- and short-term memory skills to recall past behaviour and attend to multiple response alternatives. When it comes to the issues with the SexKen questionnaire, certain problems could have been avoided if the tool had had a manual with clear instructions and a scoring sheet.

In addition, questions with sensitive or taboo content can be seen as difficult in general. Finlay and Lyons (2001) emphasised that people with LD can be even less likely to answer sensitive questions honestly, as they may be concerned about the possible consequences of their responses, for example about engaging in a sexual behaviour, particularly as they were aware of information sharing amongst professionals. What is more, as many people with LD do not have sufficient reading ability, research with this population tends to involve face-to-face interviews which are less anonymous and private than written

questionnaires, and which may lead to under-reporting of certain behaviours (Heal & Sigelman, 1990).

3.7 Thematic Analysis of Incorrect Answers

The aim of this analysis was to categorise incorrect answers to the knowledge questions from the SexKen- ID questionnaire and try to understand the source of the errors. Such an understanding is important as knowing what might lead to errors can help to avoid similar issues. I suggest what can be done in the future when interviewing people with LD, the designing of tools to avoid misunderstandings and to accurately assess the knowledge of the participants, especially regarding sex and relationships related matters. The term "errors" in this section refers to mistakes, incorrect answers, and misunderstandings. The analysis is based on the answers to the SexKen questionnaire, but it can be assumed that it is relevant to other assessments of the sexual health knowledge and to sex and relationship interviews.

The misunderstandings and errors listed below are not an exhaustive list of all incorrect or partially correct answers. The themes do not include instances when people did not answer the question or declined to respond as quantitative analysis of these was conducted in the previous section.

Whilst conducting the thematic analysis, steps suggested by Braun and Clarke (2006) were followed:

1. Familiarising yourself with the data.
2. Generating initial codes.
3. Searching for themes.
4. Reviewing themes.
5. Defining and naming themes.
6. Producing the report.

Thematic analysis focuses on the identification of patterns across data (Braun & Clarke, 2006). It is rather unusual to use it to analyse incorrect answers to a questionnaire, but it seemed an appropriate method for several reasons. First, despite the fact that the Sex-Ken questionnaire is a quantitative tool, because it was conducted as an interview, the final data was rich in details. This is also a counter-argument for those believing that people with expressive language difficulties (including people with LD) should be excluded from qualitative methods of data collection and analysis (Lloyd, Gatherer, & Kalsy, 2006). Secondly, the aim of this analysis was not just to categorise the incorrect answers, but also to interpret the data. One of the benefits of the thematic analysis is the opportunity it provides to access meanings, perspectives, and interpretations, which this analysis aims to achieve.

All the interviews were conducted and transcribed by myself. This gave me the opportunity to familiarise myself with the data. Next, an initial list of codes was generated:

I. Problems when terms have more than one meaning

II. Describing pictures

III. Different understanding of relationships

IV. Inability to provide a definition

V. Not hearing what was said

VI. Incorrect knowledge

VII. Repetition (echolalia)

VIII. Acquiescence (Yea- saying)

IX. Irrelevant comments

During the next stage, following analysis of all the codes, I decided to group the codes into five themes. The decision was made to combine “repetition” and “acquiescence” into one

theme, as they seem to have the same roots. Both phenomena can be a result of a lack of knowledge or vocabulary to answer the question or an attempt to please the interviewer (Kanner, 1943, as cited in Sterponi & Shankey, 2014).

The code "Irrelevant comments" was not included in further analysis as only one participant presented that sort of behaviour. In addition, the code "not hearing/understanding what was said" was not included as it is not specific to interviews about sex and relationships with people with LD and the mishearing can be easily corrected, and it did not affect the score. The code "Incorrect knowledge," which consisted of examples of incorrect answers to the SexKen questions, for example, that pregnancy lasted a month, was also not pursued, as the examples in it were not due to the problems with the questionnaire or interviewing style, but the lack of knowledge of the participants.

The code "Inability to provide a definition" was renamed "Participants saying they do not know the meaning of terms when they do have some knowledge." The new name better reflected the issue presented in the theme when participants expressed some knowledge of the phenomena at some point during the interviews, but at the same time stated that they did not know the definition of the term or activity.

After reviewing the codes, the final list of themes consisted of:

1. Problems when terms have more than one meaning
2. Describing pictures
3. Different understanding of relationships
4. Participants saying they do not know the meaning of terms when they do have some knowledge
5. Repetition and acquiescence

In the report, each theme will be defined, and examples provided. Next, potential sources of the error presented in the theme will be discussed as well as ways of avoiding them in the process of interviewing people with LD and designing tools for that population.

3.7.1 Theme 1- Problems when terms have more than one meaning.

This theme consists of three examples of incorrect answers were participants provided answers that were not anticipated by the questionnaire, regarding terms that have more than meaning.

As discussed in the critique of the SexKen questionnaire in Chapter 3.5.3, the question "What is meant by feeling close to someone?" proved to be especially problematic, and two participants interpreted the question literally, as a physical closeness, missing the intended point. The answers they provided were as follows: "Very close, holding hands" (P8, male, 38) and "When you near them" (P1, female, 14). The questionnaire was not trying to probe physical closeness, but the wording of the question allows some participants to take the literal meaning and respond in terms of proximity rather than relationship. Booth and Booth (1996) emphasised that participants with LD might have difficulties thinking in abstract terms. In this case "feeling close to someone" can be seen as an abstract concept.

Another example of literal understanding is the answer given by Participant 12 (female, 39) who when asked what a date was, replied: "It's Thursday."

In order to avoid this type of error when interviewing people with LD, and when developing research tools for people with LD, it is advisable to avoid asking about abstract concepts. It is preferable to use questions that refer to specific activities or events, since these are more easily understood and evaluated. In addition, for some people with LD questions about emotions have been found to be harder to answer than questions about concrete situations (Finlay & Lyons, 2001). However, when asking about relationships and feelings, it would be difficult not to ask questions about abstract concepts and emotions. A solution might be to refer to participants' personal experiences or real-life situations and asking prompt questions such as "Can you think of anything else?" When asking about feelings, pictorial representations of emotions should be used where possible, for example, smiley/sad faces or thumbs up/down as used by Siebelink et al. in their study (2006). In addition,

questions need to avoid potential ambiguity and the tools should allow for the questions to be rephrased in order to fully check the meaning of the response. Moreover, different understandings could be embraced, and the model answer sheets should allow for multiple interpretations of the term.

3.7.2 Theme 2- Describing pictures.

Some of the prompt pictures from the questionnaire portray activities such as getting married. The theme consists of 11 instances where participants described, sometimes in detail, what they could see in the picture, but not necessarily focusing on or mentioning the activity specified in the scoring system. The first four examples include cases when the answers were scored 0 points and the next two excerpts when the descriptions included correct answers.

When shown a picture of people having sexual intercourse (Figure 2) and asked: "What is this picture of? What are they doing?" Participant 26 (male, 61) said: "Right, they are lying down and both having a cuddle, saying something, whatever. The woman is touching man's knee in certain position" and Participant 5 (male, 50) stated: "That's a hand and there's foot and that's head. Cuddling." Despite the fact that both participants described the picture in detail, they did not name the activity represented, namely sexual intercourse.

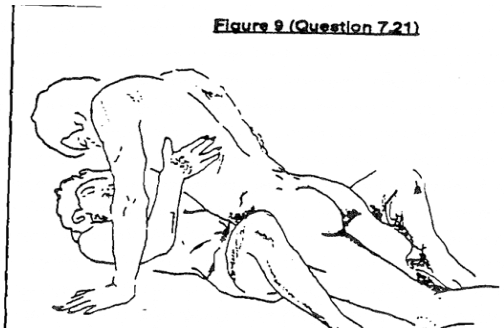

Figure 2. Prompt picture from the SexKen questionnaire presenting sexual intercourse (SexKen-ID, McCabe et al., 1999)

In the next example, the participant (P5, male, 50) when shown a picture of a couple kissing (Figure 3), said: “What is he doing there... there's a woman. It's a drawing with some people on the picture.” After a prompt question: “Do you know what they are doing?” he stated: “Blowing or something.” Again, as the activity was not identified, no points were given.

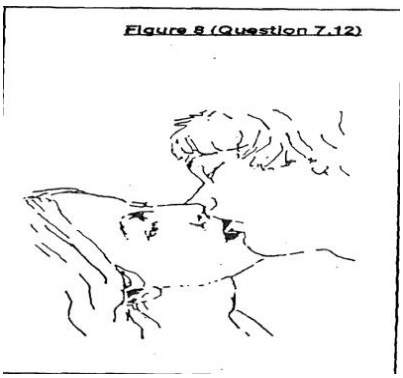

Figure 3. Prompt picture from the SexKen questionnaire- man and woman kissing (SexKen-ID, McCabe et al., 1999)

Finally, Participant 13 (male, 40) replied: “Big and fat” when shown a picture of pregnant women (Figure 4). It is unclear whether he held knowledge about pregnancy and therefore the answer was scored 0 points.

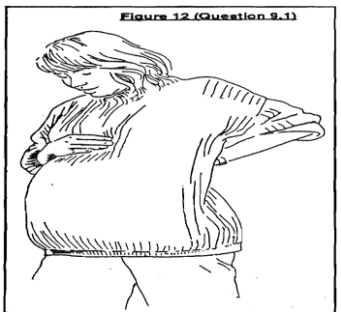

Figure 4 Prompt picture from the SexKen questionnaire- a pregnant woman (SexKen-ID, McCabe et al., 1999).

In the following examples, the features of the pictures required by the scoring manual were mentioned and included correct answers.

When shown a picture of a couple holding/cuddling each other (see Figure 5) and asked: “What are they doing?” Participant 8 (male, 38) replied: “They're holding hands, but the man has got his shoulder over the ladies shoulder and he has got his other hand near her stomach.” As the participant stated that they were “holding hands,” which was included in the scoring manual, he was awarded 2 points, but it is interesting that he described the picture in such detail, rather than just naming the portrayed activity.

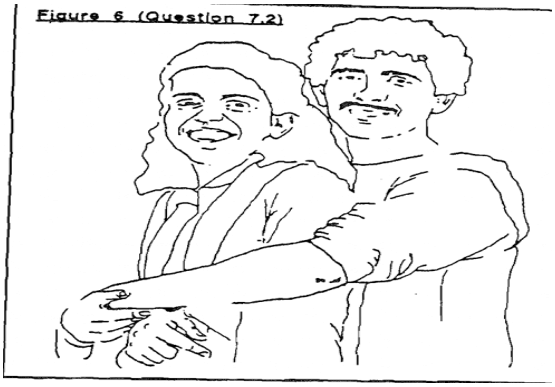

Figure 5 Prompt picture from the SexKen questionnaire- a couple hugging (SexKen-ID, McCabe et al., 1999)

In the next example, when shown a picture of a couple getting married (Figure 6), Participant 9 (female, 54) replied:

“I: What is this picture of?

P9: Partners, a couple.

I: What are they doing?

P: Holding hands.”

The participant was awarded 1 point as she mentioned people being together, but she failed to mention attributes connected with getting married.

Figure 6 Prompt picture from the SexKen questionnaire- a couple getting married (SexKen-ID, McCabe et al., 1999)

One explanation for these types of answers is that participants described the pictures in a situation when they did not know the correct answer i.e. did not know what activity the picture presented. The quality of the pictures or drawings could also be a reason why the participants were not able to correctly identify the activity presented. When it comes to the picture representing marriage, it is very culturally specific to white, Christian culture and if the participants come from different background, they might struggle with the correct answer.

To minimise the occurrence of this type of error or ambiguous answers, care needs to be taken that the participants are clear about what is expected from them, and prompt pictures, especially those portraying activities, should be easy to identify and non-ambiguous and have follow-up questions to ask if participants do not mention the intended point. The prompt question in the case of the SexKen could consist of: “What else could she/ he be doing?” which emphasises that an answer regarding activity is expected or “Why do you

think they are doing that? Furthermore, all pictures and photos should have alternatives, which include people, and situations representing different cultures, abilities etc., to help participants relate to them better.

3.7.3 Theme 3- Different understanding of relationships.

Seven participants classified people who acted towards them in a friendly manner and professionals working with them as friends, which was also found in previous research (e.g. Kelly et al., 2009). This included one participant who said that a staff member was his girlfriend and another participant who told me that another service user was his girlfriend, but she did not confirm that.

Participant 23 (female, 40) when asked: "Do you have many female friends?" named seven people including staff members and myself. Please note that the questions in the Sex-Ken questionnaire regarding male and female friends and a "special boyfriend/girlfriend" are separate questions. As some people did not know the meaning of male and female, I rephrased the questions to "lady friends." Participant 13 (male, 40) stated:

"I: So do you have many lady friends?

P13: [nods]

I: Yes, you do.

P13: Staff.

I: So staff here are your friends. In an average week, how much time do you spend with your female friends?

P13: Females [name of the manager of the day centre], [name of the staff] not her cause she is married. [name of the manager] I am very close to her and [name]."

In addition, this participant reported that a staff member was his girlfriend:

“I: Do you have a special girlfriend or boyfriend?

P13: I've got a girlfriend. That's [name] in the kitchen, staff.

I: So [name] who works here is your girlfriend?

P13: Yes, she is my girlfriend.

I: Does she know about it?

P13: Yes, she knows. I kissed her twice on the lips. Not too often.

I: Do you see her outside of here or just here?

P13: Just at [name of the day centre].”

Another person disclosed that a woman who was also attending the day centre was his girlfriend, however when she was interviewed, she did not confirm that. Overall, 25 per cent of participants in the sample had a different understanding of relationships than is generally accepted. In the study, the definition of a “friend” was self-defined by participants and whilst it has to be acknowledged that the definitions of a friendship/ relationship are individual, the consequences of categorising and treating acquaintances or professionals as close friends or boyfriends/ girlfriends can vary from interpersonal misunderstandings to potential accusations or unwanted behaviour.

Such a classification of friends appears to be common amongst people with LD. In the study by Robertson et al. (2001), 83% of participants reported having a staff member as a friend. In addition, Verdonschot, De Witte, Reichrath, Buntinx, and Curfs (2009) in their literature review found that the social network of people with LD consisted of, on average, three people, one of them usually being a professional service staff member.

Finlay and Lyons (2001) argued that such misunderstandings are the effect of the respondents interpreting the terms with a more general or a more restricted definition than the researcher does. As they point out, this is a problem with any population, but may be

particularly apparent amongst people whose life situation is very different from that of the interviewer.

As the issue appears to be unavoidable and common, a solution when enquiring about friends could be to make a note whether the participant refers to a staff member or others. In a more general context, in order to avoid issues with misunderstanding, better education is needed.

3.7.4 Theme 4- Participants saying they do not know the meaning of terms when they do have some knowledge.

This theme consists of four examples where the participants were not able to define certain terms (contraception, menstruation and homosexuality), but the information provided by them suggested that they were aware of the phenomena or that they knew what it was.

Participant 12 (female, 39) said that she did not know what a period was, but when asked if she had them, she replied: “I do, once a month.” Her answer might suggest that she knew what a period was and what it meant, but potentially believed that a definition, which she might not know, was expected from her.

The response of the next participant (P13, male, 40) suggested that he was familiar with the terms “menstruation” and “periods.” The participant had some knowledge regarding menstruation, but it was not detailed or correct. His answer was scored 0 points as it did not fit the criteria from the model answer sheet.

“I: Do you know what menstruations or periods are?

P13 (male): They are bad.

I: Ok.

P13: That's women's problem, not men's.

I: It's women's problem, so women have periods?

P13: Yes. Not men.

I: Do you know what happens when a woman has her period?

P13: [silence] It's women's problem. Nothing to do with me."

Another excerpt presents a situation where the participant (P9, female, 54) was not familiar with two terms used to describe contraception but disclosed earlier during the interview that she had a contraceptive implant, and her answer suggests that she was aware of its function.

"I: Can we talk about contraception?

P9: I don't have any.

I: Do you know what contraception is?

P9: No.

I: Do you know what birth control is?

P9: No.

I: You know the implant you have got - that's contraception. Why do you have your implant?

P9: Cause I don't want to have any babies."

In the next example, Participant 21 (female, 17), who disclosed during the interview that she was gay, did not seem to know the term "homosexuality."

"I: Do you know what homosexuality is?

P: No.

I: What about you? Are you not homosexual?

P: No.

I: If you fancy girls…

P: Oh, yea! Yes, I am."

The examples presented above might be part of a wider problem when people with LD might possess the knowledge, but due to problems with communication or limited vocabulary, may not be able to convey the information they do have. The discrepancy between receptive and expressive ability was also evident in the study by Konstantareas and Lunsky (1997) when several participants could identify terms by pointing to the appropriate picture, but they could not define these terms. In addition, individuals might not be familiar with formal terms such as menstruation, contraception, or homosexuality.

In two of the situations mentioned above, I would not have known that participants possessed the knowledge if it was not for things they had said at other points in the interview. Hence, it is important to assess their knowledge, not only by answers to the specific questions, but including information provided in the whole interview. This is in line with recommendations of other researchers. For example, Gilbert (2004) advocates that due to the range of different impairments experienced by people with LD, the interviewing requires different approaches for different individuals.

In order to minimise the occurrence of this error and as a result potential underestimation of participants' knowledge, authors of tests should avoid using formal terminology, which might be too difficult for the participants to understand and/or provide alternatives, including colloquial words. In addition, it should be specified in the manuals if/what/how many probe questions are acceptable in the situation where it is suspected that participants might possess knowledge on a certain topic. In the revised questionnaire and model answer sheet, I suggest that the researchers should attempt to use words previously used by the participants or, if possible, check with carers before the interview what words are known to the interviewee. In addition, I suggest what informal terms can be used to replace

words unfamiliar to the participants, for example, the word “condom” can be substituted with “rubber.” What is more, future tools assessing knowledge should consist of questions not requiring expressive vocabulary skills, for example asking participants to point to pictures, rather than asking for the definition of terms.

3.7.5 Theme 5- Repetition and acquiescence (yea-saying).

Acquiescence, defined as a tendency to say yes in answer to questions regardless of their content (Sigelman, Budd, Spanhel, & Schoenrock, 1981) was observed in the answers of one participant (P4, female, 52) throughout the interview. She was the participant with the lowest IQ score in the sample (45).

“I: Does everyone have to get married or not?

P: Yea.

I: Why?

P: [silence]

I: In your opinion, if people want to have sex, should they get married first or not?

P: Yea.

I: If people want to have a baby should they get married or not?

P: Yea.

I: Why?

P: [silence]”

A further two participants repeated the last word of the question. Participant 7 (female, 46) only did it once and gave a reason for doing it:

“I: Who should decide whether you have sex with someone or not?

P7: Not.

I: Who should decide?

P: Because I have Down syndrome and it's a learning disability I say 'not'."

Participant 20 (male, 52) possessed limited verbal ability and had a staff member present during the interview to assist with communication. He frequently responded to questions by repeating the last word.

"I: What do you do with your friends?

P20: Friends.

(…)

I: Sensory room with your friends. What do you talk about?

P20: About."

Acquiescence is commonly believed to be the result of submissiveness and desire to please; however, it could occur because people have not understood the question or because they do not know the answer (Finlay & Lyons, 2001). As Finlay and Lyons (2002) note, in practice, these aspects are not clearly separable. Prizant and Duchan (1981) suggest that repetitive speech (echolalia), can also serve the function of a "yes answer" (or "affirmation by repetition" Kanner, 1946, as cited in Prizant & Duchan, 1981), especially among autistic children.

Finlay and Lyons (2002) suggest using simple, clear wording, and asking for examples as ways to reduce acquiescence when interviewing people with LD. In addition, using visual cues such as pictures or visual representations of emotions and asking participants to point to them in order to minimise the need for extensive language skills, might reduce the repetition.

3.8 Summary and Discussion of the Thematic Analysis of Incorrect Answers

Interviewing participants with LD, especially those with more severe cognitive impairments and limited verbal abilities, entails some difficulties. Responsiveness, measured by the percentage of questions answered appropriately, was positively correlated with IQ in many studies (i.e. Sigelman et al., 1982). This can lead to the dilemma of whether the responses are limited by participants' inability to express themselves verbally or whether the responses reflect a lack of comprehension or insight. However, it is important that the views and opinions of people with LD are heard.

This chapter aimed to address some of the challenges by analysing incorrect responses, misunderstandings and indicating sources of the errors and ways to avoid them. The issues encountered in this research include acquiescence and last word repetition, ambiguous or meaningless responses, difficulties with abstract thinking and different understanding of terms/ phenomena/ tasks than those intended by the interviewer/ tool. Some of the difficulties included in the analysis are specific to the research topic. Querying and assessing the participants' knowledge about abstract and sensitive topics such as relationships and sexual behaviours bring additional challenges, such as difficulties with understanding the questions/ terms, embarrassment and lack of willingness to disclose certain information. Some of the errors and difficulties encountered were due to the tool used and the lack of a clear manual and scoring instructions (discussed in detail in Chapter 3.5).

Lloyd et al. (2006) in their review of qualitative research involving participants with expressive language difficulties, listed factors that can affect the credibility of answers given by individuals with expressive language and cognitive impairments (learning difficulties, dementia, neurological problems): poor or inconsistent memory for events, lack of insight or awareness, confabulated or meaningless responses, poor temporal orientation, difficulty in responding to abstract or socially reflexive questions or those relating to unfamiliar situations and acquiescence. The difficulties listed by them could also be a source of incorrect answers

of the participants in my study, as in practice the credibility of the answers is affected by many factors.

In the development of future tools, care needs to be taken to provide as many unambiguous pictures as possible (ideally coloured, good quality photos) presenting a range of people with different abilities, ethnicities etc. to help participants identify with the activity portrayed, reduce the length of the questions/sentences, and to list prompt questions and acceptable term replacements, for example, colloquial terms, rather than just formal and medical terms. In addition, visual aids such as representations of answers (for example, happy/ sad faces or thumbs up/down) are advisable and having a un- ambiguous manual and model answer sheet.

What is more, allowing interviewers to paraphrase and/or expand upon items and to add clarifying questions appears to help participants with LD reliably respond to the questions (Hartley & MacLean, 2006). In addition, I believe that when interviewing participants with LD, to ensure maximum inclusion, a flexible and individual approach should be employed, which is also recommended by Gilbert (2004) and Lloyd et al. (2006). This includes ensuring that participants are comfortable and content, for example by having frequent breaks, explaining or defining terms if necessary and avoiding asking questions on a topic not known to the participant. Successful interviewing depends a lot on the soft skills of the interviewer. In general, Hippocratic's advice: "primum non nocere" ("first, to do no harm") should be followed.

4. Chapter Four

Study 2 – Views of Parents of People with Learning Disabilities Regarding Sexual Health Knowledge of Their Children

4.1 Overview

As described in Chapter 1.1, initially I was planning to compare what young people knew about sexual health and relationships and what their carers thought they knew. Due to the difficulties with recruitment, I abandoned the idea of using parent-child pairs and divided the study into two separate ones. The aim of this study was to explore the perceived level of knowledge of children with LD as viewed by their parents. A direct comparison of the actual knowledge of a person with LD to the perception of their knowledge by a parent was no longer possible. However, as I was interested in the best and least known areas when it comes to sexual health, comparisons of these based on results from all studies will be made in Chapter 6.1.1. A second question this study tried to address was what affected parental views regarding sex education and the perceived level of sexual health knowledge of their children with LD.

The chapter will outline:

- what is known about parental factors having an impact on the perceived level of knowledge of their children,
- a hypothesised mediation model of the potential factors having an impact on parents' perceptions and views regarding the knowledge and sex education of their children,
- the changes made by myself to the SexKen-C questionnaire,
- the results of a pilot study examining the test-retest reliability of the amended tool,
- the results of the final, on-line survey for parents of children with LD.

Please note that I will be referring to the offspring of the participants as "children" even if they were over the age of 18. This is for two reasons: the first one being that despite their age, they are still children for their parents; secondly, to avoid using several different terms which could lead to confusion.

A literature search conducted by me regarding the impact of parental factors on the level of sexual health knowledge of children in the general population, in order to see which, if any, factors were associated with the children's level of knowledge (actual or perceived), did not return many results. The term "parental factors" refers in this chapter to any variables related to parents, for example stress levels. Sanders and Mullis (1988) reported that students' (no disabilities) sexual knowledge was not related to the perceived parental influence or attitudes. Mueller and Powers (1990) found that participants (college students) who perceived their parents as friendly, relaxed, attentive, precise, dramatic, and good communicators during sex- related conversations reported lower sexual information accuracy, which was an unexpected result. Fisher (1986b) found no difference in the sexual knowledge of adolescents without disabilities between those who came from "high communication" families to those from "low communication."

However, research conducted amongst the general population suggests that parental communication with their children regarding sex was related to later sexual initiation, a smaller number of sexual partners and better contraceptive use (Fisher, 1986a; DiIorio, Pluhar, & Belcher, 2003; Ogle, Glasier, & Riley, 2008; Turnbull et al., 2008). Parent-child communication appears to be affected by gender, with mothers communicating more with their daughters (DiIorio et al., 2003). A literature review conducted by DiIorio et al. (2003) showed that other socio-demographic variables, such as age, race, ethnic group, education, occupation, and religion did not show consistently strong associations between them and the within family communication. The impact of those factors will be discussed in more details in Chapter 4.1.1. Research into psychological variables suggests that factors such as parental perception of their own knowledge, parental confidence and comfort are important factors in

sex-related communication in families with children without disabilities (DiIorio et al., 2000; DiIorio et al., 2003; Guilamo-Ramos, Jaccard, Dittus, & Collins, 2008; Jerman & Constantine, 2010).

As noted by some researchers (Garbutt, 2008; Jahoda & Pownall, 2014), individuals with LD have fewer formal and informal sources of sexual information, and with that in mind, it can be assumed that parents might play a more important role in the sex education of disabled children. Most participants with LD interviewed by Williams, Scott and McKechanie (2014) in Scotland pointed to their parents as the main source of information about relationships and sex. However, the study by Pownall, Wilson and Jahoda (2017) investigated this aspect and concluded that despite the social exclusion of young people with disabilities (LD and physical), they did not appear to turn to their parents for health- related information. What is more, research conducted with families with children with LD suggested that both the young people and their families found it difficult to discuss sexual matters together (Pownall, Jahoda, Hastings, & Kerr, 2011). Therefore, it is important to examine what factors play a role in the perception of knowledge and the extent of sex-related communication between parents and their children with LD in order to enhance the role of parents as sex educators of their children.

Pownall et al. (2012) compared the experiences of mothers of children with LD and those without disabilities in relation to delivering sex education. They observed in their research that mothers of young people with LD were more likely to initiate discussions about sexual matters with their child, whereas parent–child communication with young people without disabilities was more likely to be mutually initiated. In addition, the mothers of children with LD spoke about fewer sexual topics overall than did the mothers with offspring without disabilities. In the study, the mothers of children with LD attached less importance to discussing abstinence, peer pressure, and STDs than did the mothers of offspring without disabilities (Pownall et al., 2012). Group (LD vs no disability) and gender differences were minimal in relation to the mothers' confidence and comfort in discussing sexual health topics

with their child, Pownall et al. (2012) reported a trend for the mothers of young people without disabilities to be less confident or comfortable when talking about some sensitive topics, in particular sexual pleasure than were the mothers of young people with LD. The mothers also observed that their children with LD found the sexual topics more difficult to understand, although they did not anticipate that their children would be any more uncomfortable or embarrassed discussing these topics than children without disabilities. In general, the mothers with children with LD were more cautious in their attitudes toward sexuality of their child Pownall et al. (2012).

Some information is available regarding reasons for parents not discussing sexual matters with their children with LD. Garbutt (2008) wrote that parents reported a lack of clear, concise information about what and how to discuss sex and relationships with their offspring, and the need for more support to do it. Swain and Thirlaway (1996) asked professionals working with parents of children with LD to list reasons why they believed the carers avoided approaching the topic of sex with their children. The main factor, according to the professionals, was that the parents denied their child's sexuality and were "thinking of them as babies" (p.60). Other reasons included the daily burden of care, the parents' belief that exposure to sexual experience was pointless and dangerous, the denial of parents' own sexual needs and parents' early experiences with their children (i.e. guilt or grief; Swain & Thirlaway, 1996). Two studies regarding the parental perspective on communication about sex in families of children with autism spectrum disorders found that the parents' perceptions of a child's behaviour and comprehension were associated with the level of within-family communication about sex-related issues (Ballan, 2011; Ruble & Dairymple, 1993).

As this is an exploratory research, it aimed to clarify which factors, if any, can be linked to the level of knowledge or the perception of it. With limited information on the role of psychological factors and no recommendations emerging from previous research, a decision was made to examine the role of three parental variables on the perceived level of knowledge (PLK) of their children: personality, level of stress and locus of control. In

previous research, it was shown that parents of children with LD showed higher stress levels compared to parents of non-disabled children (Hassall & Rose, 2005). Stress can affect various aspects of our lives, including well- being, physical health and cognition, and at the same time, it is inherent part of our lives. Hence, a decision was made to include it as a variable in this study. Similarly, our personality influences how we see the world and perceive events. The locus of control is a concept that refers to how strongly people believe they have control over the situations and experiences that affect their lives. In the context of this study, I was mainly interested in the fact whether participants feel responsible for the education of their child and how is this linked to the perceived level of knowledge. All of these variables can affect perception, in this case the perception of child's knowledge, but also how the participants see their role of the sex educator of their child. Therefore, it is important to check which factors, if any, are associated with the PLK and to gain insight into the level of sexual health knowledge of people with LD and how it could be improved. Each of these factors and their potential influence will be discussed below.

In addition, as the results of previous studies regarding the impact of sociodemographic variables on the within family communication about sex were inconsistent, a decision was made to include in the on-line survey a range of socio-demographic questions. These included age, marital status, religion and religiosity, level of education, employment status and ethnicity, as well as questions regarding level of functioning and support needs of the child with LD, to test if any of these factors had an impact on the level of the perceived knowledge of the child. Knowing which parental and child variables play an important role in parental communication and attitudes to sex education of the children can inform the creation of more sensitive support and materials to help families deal with the sexual development of their children.

Please note that, as to my knowledge, there were no previous studies regarding the impact of any parental/ family factors on the actual or perceived level of knowledge, apart from Fisher (1986b), Mueller and Powers (1990) and Sanders and Mullis (1988), which

showed no association between parental factors and the level of knowledge of non-disabled children, all hypotheses for the study are based on indirect evidence, for example regarding the relationship between personality factors and communication. The aim of the study is to better understand the factors that can influence the level of knowledge of people with LD.

4.1.1 Parental factors and the PLK.

As mentioned above, only a limited number of studies regarding the impact of parental factors on a child's knowledge, both in the general population and offspring with disabilities, were found. Therefore, this section will outline what is known about the relationships between different personality aspects, parental stress levels and locus of control, communication, and knowledge.

4.1.1.1 Personality.

Research from the general population showed that high levels of extraversion, agreeableness, conscientiousness, and openness, and low the levels of neuroticism of carers were correlated positively to parental warmth and better behavioural control of their children (Prinzie, Stams, Deković, Reijntjes, & Belsky, 2009). Such a configuration of parental personality traits is believed to be the most beneficial to the child's positive behaviour and adjustment (Oliver, Guerin, & Coffman, 2009). It has also been shown that mothers and fathers who were less neurotic, more agreeable, more extraverted and more conscientious reported higher involvement and communication with their non-disabled adolescent children (Oliver et al., 2009). In addition, people describing themselves as conscientious were more task orientated, diligent and scrupulous (Costa & McCrae, 1992). It can be speculated that participants who score high on extraversion, agreeableness, conscientiousness, and openness, and have low levels of neuroticism are more involved in raising the children and communicate better with their offspring and as a result, they will perceive their children to be knowledgeable about sex and relationships.

When it comes to relationships between personality and attitudes towards sex in general, research shows that openness to experience was associated with low sexual nervousness and attitudes that were more liberal (Heaven, Fitzpatrick, Craig, Kelly, & Sebar, 2000). As mentioned previously, parental confidence and comfort were examined and proved an important factor in playing a role in the parent-child communication about sex in the general population (DiIorio et al., 2003). Thus, it can be hypothesised that individuals scoring high on the openness to experience scale present more positive attitudes towards sex and find the topic easier to discuss with their children, which results in the child's higher level of knowledge. Therefore, the first hypothesis is that participants who score high on extraversion, agreeableness, conscientiousness, and openness, and have low levels of neuroticism will report greater perceived sexual health knowledge of their children with LD.

4.1.1.2 Stress.

Stress levels of parents of children with LD is a well-researched aspect. In previous studies, the stress levels of parents of disabled children were compared to the stress levels of parents of non-disabled children (e.g. Baker, Blacher, Crnic, & Edelbrock, 2002). Studies also looked at factors mediating the stress levels i.e. social support or parental cognition (e.g. Hassall, Rose, & McDonald, 2005). Hassall and Rose (2005) in their review of the literature on the stress levels and adaptation of parents of children with LD reported that most studies noted higher stress levels among parents of children with LD compared to parents of non-disabled children, with similar levels of parenting stress between mothers and fathers. They also concluded that the association between the stress levels and the level of the disability of the child was not clear (Hassall & Rose, 2005). However, two child variables known to be associated with higher parental stress are adaptive functioning and behavioural problems (Hill & Rose, 2009). Parenting stress was also found to be higher amongst parents of children with autistic spectrum disorder (ASD), compared to parents of children with Down's syndrome and without disabilities (Estes et al., 2009; Wolf, Noh, Fisman, & Speechley, 1989). The results could be down to children with ASD demonstrating higher levels of

problem behaviour (Estes et al., 2009). Lessenberry and Rehfeldt (2004) argued that parental stress could have a profound impact on the development and progress of a child with a disability. Osborne and Reed (2010) found in their study involving parents of children with ASD that there was a significant, negative correlation between parenting stress and parent-child communication (measured as a part of Parent-Child Relationship Inventory). Therefore, another of the hypotheses is that parents presenting high stress levels will report low levels of perceived knowledge of their children.

4.1.1.3 Locus of control.

In general, individuals with an internal locus of control see events as a result of their own actions or abilities and therefore under their potential control. External locus of control refers to the perception of actions as being not linked with behaviours or attributes of the person, but dependant on luck, chance, or fate and thereby beyond personal control (Rotter, 1966). Research in the general population showed that those with an external locus of control found communication less rewarding and tended to avoid it (Rubin, 1993). Individuals with a higher internal locus of control were found to be more willing to resolve personal problems (Joe, 1971). Internal locus of control was also found to be positively correlated with academic achievements and involvement in intellectual activities (Joe, 1971).

Following a literature search, it would appear that the locus of control among parents of children with LD has only been examined in the context of the levels of stress, anxiety and depression (Friedrich, Wilturner & Cohen, 1985; Hassall et al., 2005; Hill & Rose, 2009; Jones & Passey, 2005; Lloyd & Hastings, 2009) and children's behavioural problems (Campis, Lyman & Prentice-Dunn, 1986; Roberts, Joe & Rowe-Hallbert, 1992). The results of these studies were consistent and showed that parents with an external locus of control were experiencing higher levels of stress, anxiety, and depression. Hamlyn-Wright, Draghi-Lorenz and Ellis (2007) compared parents of children with autism, Down's syndrome and no disability and found that parents of autistic children had significantly lower levels of internal

locus of control than both parents of children with Down's syndrome and parents of children with no LD, with no significant difference between these last two groups.

Hence, the hypothesis is that participants, who have internal locus of control, will report greater PLK of their children. This is because they will see the sex education of their children as their responsibility, find communication more rewarding, have lower levels of stress and be more willing to resolve personal problems.

4.1.1.4 Age and gender.

Parental and offspring gender are well-documented factors playing a role in sex communication, with mothers communicating more with their daughters in the general population (e.g. DiIorio et al., 2003) as well as mothers of daughters with LD tending to discuss more sex- related topics overall than did mothers of sons (Pownall et al., 2012). In addition, a survey conducted by Durex et al. (2010) with the general public showed that girls were more likely to receive sex education at schools. When it comes to age, there is evidence suggesting that the age of parents (Cuskelly & Bryde, 2004) and the age of members of the public (Karellou, 2003) had an impact on attitudes regarding the sexual expression of people with LD. In the general population, older parents avoided sex communication with their children (Regnerus, 2005). Mothers of young people with LD generally discussed sexual matters with their child at a later age than did mothers of offspring without disabilities, however when mothers' occupation was controlled for, the difference became nonsignificant (Pownall et al., 2012). Analysis of the relationship between parental age and the PLK in this sample would be difficult as it can be assumed that the older the parents, the older the children. Therefore, the PLK will be potentially confounded by the age of the child. Hence, the only hypothesis regarding these factors is that reported PLK of the daughters will be higher than sons.

4.1.1.5 Religion and religiosity.

DiIorio et al. (2000) found that mothers of non- disabled children, who described their religious belief as important to them, discussed a greater number of sex-related topics with their adolescents. The authors explained that mothers who were secure in their religious beliefs might also hold firm beliefs about sex and be more certain about what to say to their adolescent and when to say it. Another explanation suggested by the authors was that those with strong religious beliefs had a heightened sense of duty as a parent to educate their children on moral and ethical issues, including issues related to sex (DiIorio et al., 2000). However, religious activity was not linked to the level of communication (DiIorio et al., 2000). Regnerus (2005) reported similar findings- the more important religion was to the parent, the more frequently they reported communicating with their non-disabled children about sex and birth control. Further analysis suggested that when religious parents stated they were talking to their children about sex and birth control, the conversations were about the morality of adolescent sexual involvement. Regnerus (2005) also found that regular church attendance contributed to less frequent conversations both about birth control and sex, but to more frequent conversations about the moral issues involved in adolescent sex. The researcher also noted that parents who attended religious services frequently also reported greater unease with sex-related communication, even after controlling for the frequency of such communication (Regnerus, 2005).

When it comes to the type of religion, in the study conducted by Regnerus (2005) in the USA, parents who affiliated with Black Protestant churches talked the most and with the greatest ease about sex-related topics. Roman Catholic, Jewish and Mormon parents reported not feeling comfortable to initiate sex-related conversations with their non-disabled children (Regnerus, 2005).

No studies regarding the impact of religion on knowledge or communication amongst families with children with disabilities were found. Any communication includes both the

transmission of facts and values. Based on the results of the studies conducted in the general population, it would appear that when it comes to sex-related conversations between religious parents and their children, parents might believe that their primary responsibility is to convey normative, rather than informative, messages about sexual behaviour. However, it can be assumed that any conversation, even just values- based, can potentially draw attention to facts and is better than having no discussion at all. For example, discussion about prohibition of pre-marital sex can convey some knowledge about pregnancies and STIs. Therefore, the hypothesis for this study is that participants, who identify themselves with any religion and report to be active in the practice of it, will report higher PLK of their children than those who do not.

4.1.1.6 Education and income.

Research conducted by Sprecher, Harris and Meyers (2008) amongst non-disabled University students showed that the higher the participant's social class, the more sex education reported from their parents. The social class in their study was assigned based on self-assessment and the level of education of the parent. It can be assumed that the level of household income is associated with the social class. The higher the social class, the higher the income and parental education. Therefore, the hypothesis is that the higher the household income and level of education of participant, the greater the PLK of the child.

4.1.1.7 Parent-child communication.

The results of studies conducted amongst families with non- disabled children regarding the impact of sex- related communication on the level of knowledge did not show any association. However, as mentioned previously, it was noted by many researchers (Garbutt, 2008; Jahoda & Pownall, 2014) that individuals with LD have fewer formal and informal sources of sexual information and are supervised most of the time. Therefore, it can be assumed that parents might play a more important role in the sex education of disabled children, compared to non-disabled. A literature search regarding the link between

communication and the level of knowledge among families who have children with LD, revealed only three studies. Previous research concentrated on the factors having an impact on communication and not the association between communication and the level of knowledge. The results showed that the level of parental stress (Osborne & Reed, 2010) and parental perception of a child's comprehension and behaviour (Ballan, 2011; Ruble & Dairymple, 1993) were linked with the frequency and quality of communication regarding sex.

When it comes to factors having an impact on the occurrence of sex-related discussion in families with non-disabled children, as mentioned previously, confidence and comfort were shown to be important factors playing a role in the communication (DiIorio et al., 2000; DiIorio et al., 2003; Guilamo-Ramos et al., 2008; Jerman & Constantine, 2010). Therefore, the hypothesis related to parent-child sex- related communication is that parents, who report discussing sex with more confidence and comfort and more frequently, will report a greater PLK of their children.

4.1.2 Relationship between children's variables and PLK.

In addition to parental factors, I was also interested if child variables were associated with PLK. Correlation between the knowledge scores and IQ was observed in Study 1. This was shown in several previous studies as well (e.g. Edmonson & Wish, 1975; Ousley & Mesibov, 1991). Therefore, the hypothesis is that the higher the level of functioning of the child (as described by the parents) the higher the level of the PLK.

Participants from Study 1 who reported having some form of sex education scored significantly higher on the SexKen questionnaire. The positive impact of sex education on knowledge was shown in previous research as well (e.g. Lindsay et al., 1992; Penny & Chataway, 1982). Therefore, another hypothesis is that children who received formal sex education will be assessed by their parents to be more knowledgeable about sexual health and relationships.

4.1.3 Research questions and hypotheses.

The study has two main research questions:

1. What do parents of children with LD rate their children's level of knowledge to be (perceived level of knowledge - PLK)?
2. What is the relationship between parental and children's variables and PLK of children with LD?

The hypotheses for the study can be divided into three groups: those associated with parental psychological factors, parental sociodemographic variables, and children's variables. Note: PLK refers to the perceived level of knowledge of the child as reported by the parent.

I. Parental psychological factors

1. There will be a positive correlation between parental extraversion, agreeableness, conscientiousness, and openness and the PLK.
2. There will be a negative correlation between parental neuroticism and the PLK.
3. There will be a negative correlation between parental stress levels and the PLK.
4. There will be a negative correlation between parental locus of control and the PLK.
5. There will be statistically significant differences on the PLK by the level of quantity, confidence and comfort of parent- child sex-related communication.

II. Parental sociodemographic variables

6. Participants identifying with any religion will report higher the PLK of their children.
7. There will be a positive correlation between parental religiosity and the PLK.
8. There will be a positive correlation between household income and the PLK.
9. There will be a positive correlation between parental education and the PLK.

III. Children's variables

10. The higher the level of functioning of the child with LD, the higher PLK.

11. Parents of children who received formal sex education will report a high PLK.
12. Parents will report that their daughters present higher PLK than sons.

4.2 Modifications to the Sex-Ken Scale and Pilot Study

4.2.1 Adaptations of the Sex-Ken scale.

As mentioned previously, after unsuccessful attempts to recruit parent-child pairs to conduct face-to-face interviews, a decision was made to transform the SexKen- C (version for carers) into an on-line survey in order to examine parents' perceived level of knowledge of their children. The SexKen questionnaire consists of questions regarding sexual experiences and needs, as well as knowledge, and it is quite lengthy (198 questions). In addition, I wanted to examine which factors have an impact on parental views and their perception of their children's knowledge. This meant including additional questionnaires, which would make the survey very long and time-consuming and as a result, would have a negative impact on recruitment, which was predicted, based on previous experiences, to be difficult anyway. Therefore, some compromises had to be made. As knowledge of people with LD was the main focus of the research, only knowledge questions were included in the on-line version of the SexKen questionnaire.

The decision meant that some changes had to be made to the SexKen-C questionnaire. Questions were rephrased to be specific to the participant's child only, rather than all people with LD, e.g. question: "What would people with intellectual disability say 'homosexuality' is?" was changed into "Does your child know what homosexuality is?" In the SexKen-ID version, the question was worded in the following way: "What is homosexuality?"

In addition, all questions were amended so that the answer could be given using 5 points Likert type scale (unsure; no, not at all; partly; mostly and completely). In the original version, the administration was in the form of an interview and the format of answers was varied, including open-ended questions. Also, some of the original questions had pictorial

prompts, i.e. a picture of a couple getting married, followed by the question: “What would people with intellectual disability say this is a picture of?” As the inclusion of prompt pictures would require having an open-ended response format, these kind of questions were rephrased to: “When shown a picture of a couple getting married, do you think your child would know what the picture is about?”

The main criteria regarding the changes to the questionnaire was that questions about each aspect of the sexual health, relationships, sexual interactions etc. were asked once. For example, there are three questions regarding understanding of public/private in the original SexKen-C tool: “Where would a person with intellectual disability and a partner do any of these things [sexual interactions]?” “Where would a person with intellectual disability think it is OK to do these things?” and “Where would a person with intellectual disability think other people do these things?” This was changed to one question assessing the knowledge regarding understanding of privacy: “Does your child know where it is OK to have sexual contact (understands public/private)?” Another example concerns questions regarding orgasm. The following questions can be found in the SexKen-C: “What answer would a person with intellectual disability give to the question: “How would a person with intellectual disability define the concept of 'having an orgasm'?” “Would a person with intellectual disability think that a man can have an orgasm?”, “Would a person with intellectual disability think that a woman can have an orgasm?”, “What answer would a person with intellectual disability give to the question: ‘What happens when a woman has an orgasm’?” “What answer would a person with intellectual disability give to the question: ‘What happens when a man has an orgasm’?” This was changed to one, general question about orgasm: “Does your child know what having an orgasm means? and a question for each sex: “Does your child know what happens when a man has an orgasm?” and “Does your child know what happens when a woman has an orgasm?” In addition, only questions asking about sexual organs (penis, vagina, breast) and their functions from the Body Parts Identification sub-section were retained and questions regarding other body parts were removed (i.e. “Would people with an

intellectual disability know where the nose is? Label the nose according to their view; what would people with intellectual disability say the nose is used for?"). The total number of questions came to 60 (96 in the original version).

It is important to note that the changes made to the scale potentially made it easier to get high marks on each topic as no ambiguous pictures and no open definition questions were included. In addition, the lack of open-ended questions meant that the scoring did not have to be done using a contestable scoring system. This is discussed in more details in Chapter 3.5.

Professor McCabe, the author of the SexKen scale, was informed by email about the changes made to the scale and asked if she had any objections or comments. She replied that in her opinion the changes should not affect the validity of the scale. In addition, four professionals in the field of the sexual health knowledge of people with LD (3 practitioners- 2 sex educators and one person working with parents of disabled children - and 1 researcher in the field of LD and sexuality) were asked for the comments regarding clarity and accuracy of the questions. Minor changes, mainly regarding wording, were implemented following their feedback. The revised scale is included in Appendix 5.

The sections/ topics included in the on-line version of the questionnaire measuring perceived level of sexual knowledge of children of participants were: marriage (1 question), body parts (9), sex (1), menstruation (4), sexual interactions (17), contraception (5), pregnancy, childbirth and abortion (11), sexually transmitted diseases (8), masturbation (3) and homosexuality (1). The format of the answers (apart from the last question) to the perceived knowledge survey was: unsure; no, not at all; partly; mostly and completely. The response "unsure" was scored with the average score to the question given by other participants, "no, not at all" was given 0 points, "partly"- 1 point, "mostly"- 2 points and "completely" 3 points. The last question asked about a number of contraceptive devices known by the child and was scored 1 point, if "1-2 devices" were known, 2 points if "3-4"

and 3 points for knowing “5 or more” making it a maximum of 180 points that could be achieved for the section.

4.2.2 Pilot study.

4.2.2.1 Method.

Only the adapted SexKen- C questionnaire was included in the pilot study, as the other measures intended to be used in the main study were not amended in any way and possessed good psychometric properties. No other questions regarding, for example, the sex of participants or other socio-demographic information were asked, apart from the age of the child, for the purpose of the pilot.

In order to test the reliability of the amended scale, a test-retest amongst parents of non-disabled children was conducted. The survey was created using Qualtrics, which is a platform for generating and distributing on-line tests. Completing the survey twice required participants to leave their email address in order for the researcher to match the answers and to be contacted to remind them to do it again. Ethical permission was sought and granted to ask participants for email addresses as this affected the anonymity of the survey. Qualtrics allows for the setting up of an automatic reminder to be sent to participants to complete the survey again. If the survey was not completed after a period of two weeks and after receiving an automated reminder, I sent a request by email asking the participants to do it one more time.

An inclusion criterion was having a child of any age, as this was going to be one of the two inclusion criteria for the main study. Potential participants were recruited via personal requests sent to acquaintances, adverts on social media (a post on the Social Science Research Group on Facebook, which was then shared by myself and few of my friends, and Facebook site of the charity I work for), fora and websites for parents (www.mumsnet.co.uk, www.madeformums.com, www.justparents.co.uk, www.parenting.co.uk). However, all websites except for the last one removed my advert quickly as they did not accept entries

with links in them. In addition, the SONA- Psychology research participation system was used to recruit Anglia Ruskin University students, who could gain 1 credit for taking part.

4.2.2.2 Participants and results of the pilot survey.

Ten people completed the pilot survey twice. No additional questions, for example regarding the age or sex of the participants, apart from the age of the child (eldest, if more than one) were asked. Table 13 summarises the age of the children of participants, the time between completion of the survey and correlation between the two sets of answers. The mean number of days between completing it for the first and second time was 14 days (between 5 to 27 days). The mean age of the child was M = 12.4, SD = 7.47. The data was downloaded from Qualtrics into SPSS Statistics Data Editor in order to correlate two sets of data (obtained at time 1- T1 and time 2- T2) to establish the reliability of the adapted questionnaire. Questions, which were not answered twice were removed from the analysis. First, Pearson's correlation coefficient was checked for each person, correlating answers given at T1 and T2. The correlation between answers given for the first and second time ranged between r = .23 and r = .96 - see Table 13. Next, all scores at T1 and T2 were correlated. Pearson's correlation coefficient was r (658) = .73, p < .001. According to Koo and Li (2016) values between 0.5 and 0.75 indicate moderate reliability, values between 0.75 and 0.9 indicate good reliability, and values greater than 0.90 indicate excellent reliability. Overall, the correlation was acceptable for the tool to be assessed as being reliable. Cronbach's alpha was also calculated for the tool and it was equal .83. George and Mallery (2003) provided the following rules of thumb for Cronbach's alpha coefficient: _ > .9 – Excellent, _ > .8 – Good, _ > .7 – Acceptable, _ > .6 – Questionable, _ > .5 – Poor and _ < .5 – Unacceptable.

Table 13

Age of the child, the time between completions of the survey (days) and the correlation between the two sets of answers.

Participant	Age of child	Time	Correlation	*p*
1	30	5	.83	.001
2	10	14	.26	.034
3	6	15	.64	.001
4	19	20	.95	.001
5	12	17	.91	.001
6	8	27	.74	.001
7	11	10	.23	.062
8	8	8	.96	.001
9	15	14	.26	.034
10	5	13	.80	.001
Mean	12.4	14.3	.66	

I had a look at the individual questions to check if any was associated with low correlations, but no pattern was observed. A general issue with questionnaires assessing knowledge is that participants can obtain new information between completing the tests. In this case, as the questionnaire was measuring the perceived level of knowledge, completing the test for the first time could have potentially prompted participants to discuss certain topics with their children and as a result, their estimates of the knowledge at T2 were higher than at T1, which could be a reason for lower correlation coefficients.

4.3 Main Study Method

Following the pilot study, a full version of the survey, which included sociodemographic questions, the Big 5 Inventory (BFI), Locus of control (LOC) and the Perceived Stress Scale (PSS) was created using Qualtrics - a platform for creating and distributing on-line surveys. Information about the participants, recruitment, as well as the results and information about the survey, which formed the basis for Study 2 are outlined in this chapter.

4.3.1 Participants.

Overall, 92 participants started the survey and 83 completed it. All participants confirmed that they had a child with LD and lived in the UK, which were the inclusion criteria. Eighty women and three men took part in the study. The average age was 46 (*SD* = 11). Other sociodemographic data can be found in Table 14.

Table 14

Participant's sociodemographic data

Characteristic	Frequency	Percentage
Relationship status		
Married/ civil partnership	46	55.42%
Living with a partner	16	19.27%
Single	9	10.84%
Divorced	9	10.84%
Widowed	3	3.61%
Religion		
Christian	38	45.78%
No preference/no religious affiliation	36	43.37%
Prefer not to say	2	2.40%
Other	7	8.43%
Religiosity		
Does not apply/ prefer not to say	27	33.75%
Active	5	6.02%
Somewhat active	19	22.89%
Not very active	12	14.45%
Not active	20	24.09%
Employment		
Employed/ self-employed full-time	20	24.09%
Employed/self-employed part-time	32	38.55%
Looking after house/child(ren)	23	27.71%
Unemployed	2	2.40%
Retired	3	3.61%
Students/ in training	3	3.61%
Ethnicity		
White English	68	81.92%
White Scottish	2	2.40%
White Welsh	2	2.40%
White Irish	2	2.40%
Other white	5	6.02%
Other Asian background	1	1.20%
Caribbean	1	1.20%
Other mixed background	1	1.20%
None of the above/prefer not to say	1	1.20%

Education		
Degree or above	46	55.42%
A levels	18	21.68%
GCSE	11	13.35%
Apprenticeship	1	1.20%
No qualifications	7	8.43%
Household income per year		
More than £40k	27	33.75%
Between £30k and £40k	7	8.75%
Between £20k and £30k	16	20%
Between £10k and £20k	16	20%
Less than £10k	14	17.5%

When it comes to the sex of the disabled child, there were 54 men and 29 women, with the average age of the child being *M* = 15 years (*SD* = 6.5, min = 4, max = 37). The participants were asked to classify the level of their child's disability and the results were as following: mild (16.87%, 14), moderate (54.22%, 45) and severe (28.92%, 24). Next, parents were asked about their children's independence level, ranging from "requires support for most activities" (55.42%, 46), "needs few hours of support a day" (26.51%, 22), and "requires support, but less than few hours a day" (14.46%, 12) to "no or occasional support" (3.61%, 3). Participants were also asked about the diagnosis of their child if there was any. It was an open-ended question and therefore the diagnosis given varied in the terminology used and details given. Most children had multiple diagnoses. A summary of the frequency of diagnosis can be seen in Table 15.

Table 15

Summary of the diagnosis of the children of the participants

Diagnosis	Frequency
No diagnosis	2
Learning disability	3
Down's syndrome	13
ASD	29
Other diagnosis: deaf, Smith- Magenis syndrome, ADHD, left side hemiplegia, acquired brain injury	5
Multiple diagnoses[a]	31
Total	83

[a] this category includes all instances when parents listed more than one diagnosis

Please note that that the diagnoses listed as "other," apart from the Smith-Magenis syndrome, do not necessarily entail LD. However, as mentioned previously, in order to proceed to the survey, the participants had to confirm that they had a child with LD. Participants were not provided with a definition of LD. Therefore, it is possible that some of the children might not have had LD in the formal meaning.

4.3.1.1 Recruitment.

Overall, approximately 500 (+/- 10) organisations from across the United Kingdom supporting parents of children with LD were contacted by email asking for help with dissemination of the link to the survey between September 2017 and January 2019. The email outlined the PhD project and practical implications of the research. The recipients were asked to include the link to the survey in their newsletters, email groups, or social media sites. Relevant organisations were identified by checking county councils' websites and looking for the support offered to parents of disabled children in the county. Moreover, I contacted all groups in the UK existing under the umbrella of the National Network for Parent Carer Forum and the Carers Trust. In addition, internet and social site (Facebook and Twitter) searches were conducted for support groups for parents of children with LD, challenging behaviour and rare chromosomal disorders with accompanying LD. Out of the 500 organisations and groups, 27 representatives/ administrators contacted me back, confirming that they would disseminate information about my research, and nine informed me that they would not. Information regarding the survey was also posted on the Choice forum (platform for people with LD, their parents, carers and professionals), my Twitter account, the Facebook site of the charity I work for (supporting people with mental health problems and LD), and emails with the link sent to my colleagues and acquaintances (9).

Potential participants could have been included in a prize draw (£50 M&S voucher). That required leaving an email address and affected anonymity. Ethical permission to ask for email addresses was applied for and obtained.

4.3.2 Materials.

The materials used in the study included:

- set of questions about sociodemographic data,
- questions regarding participants' children with LD,
- questions assessing perceived sexual knowledge of the children of participants (adapted from the SexKen- Cquestionnaire, more information can be found in Chapter 4.2.1),
- questions regarding parental views on sex education and communication,
- questionnaire assessing personality- the Big Five Inventory (BFI) scale,
- questionnaire measuring locus of control (LoC),
- tool assessing participants' level of stress- Perceived Stress Scale (PSS).

4.3.2.1 Sociodemographic data.

The questions and proposed answers were based on the 2011 UK Census (Office for National Statistics, 2011).

1.	**Are you:**	**6.**	**What is your ethnicity/culture**
□	Married/civil partnership	□	White (English)
□	Single	□	White (Scottish)
□	Divorced	□	White (Irish)
□	Living with partner	□	White (Welsh)
□	Widowed	□	Gypsy or Irish traveller
□	Prefer not to say	□	Other white
2.	**How many children have you got:**	□	Caribbean
□	1	□	African
□	2	□	Other Black background
□	3	□	Indian
□	4	□	Pakistani

- 5
- More than 5

3. What, if any, is your religious preference?

- Christian
- Hindu
- Muslim
- Buddhist
- Sikh
- Jewish
- No preference / No religious affiliation
- Prefer not to say
- Other

4. How active do you consider yourself in the practice of your religious preference?

- Very active
- Somewhat active
- Not very active
- Not active
- Does not apply / Prefer not to say

5. How would you describe your current employment status?

- Employed/self-employed full time
- Employed/self-employed part time
- Unemployed / Looking for work
- Student/in training
- Looking after house/child(ren)
- Retired

- Bangladeshi
- Chinese
- Other Asian background
- White and Black Caribbean
- White and Black African
- White and Asian
- Other mixed background
- Other ethnic background
- None of the above/prefer not to say

7. If you were not born in England, how long have you been living here? ……years

8. What is your country of origin?……

9. What level are you educated to:

- No qualification
- Apprenticeship
- GCSE
- A Levels or equivalent
- Degree or above
- Other qualifications

10. What is your household income (per year):

- Less than £10k
- £10-20k
- £20-30k
- £30-40k
- More than £40k

4.3.2.2 Information about participants' children with LD.

Next, questions asking for information about participants' children with LD were asked:

- child's age,

- child's sex,

- "How would you classify the level of your child's disability?" with answers to choose: mild, moderate and severe,

- "Does your child have a diagnosis? If yes, what is it?" with an option to type it in,

- "What is your child's independence level?" with a choice of: requires support for most activities, needs few hours of support a day, requires support, but less than few hours a day, no or occasional support.

4.3.2.3 Perceived sexual knowledge.

The modified tool (adapted version of SexKen- C) is described in Chapter 4.2.1. The reliability of the perceived knowledge questions derived from the SexKen was checked using Cronbach's alpha = .98, $p < .0005$. George and Mallery (2003) reported that as a rule of thumb, Cronbach's alpha coefficient above 0.9 suggests excellent reliability. The result is very high though, which could be down to the fact that the sample was not very large. Coaley (2014) recommended that the reliability of a tool should not be measured in the samples below 100 participants.

4.3.2.4 Questions regarding views on sex education and sex-related communication.

There were nine questions assessing parents' views regarding sex education and sex-related communication (see below). The questions were developed based on the literature review with the purpose of gathering information regarding ease and frequency of communication and views on sex education.

1. Has your child had any form of sex education? Format of the answers: no, not at all; a little; quite a lot; a lot; unsure.
2. Do you think that more sex education is needed for people with learning disabilities? Answers: no, not at all; a little; quite a lot; a lot; unsure.
3. Do you think your child would like to know more about sexuality? Answers: no, not at all; a little; quite a lot; a lot; unsure.
4. Who has given your child information on sex? Answers (more than one answer could be chosen): yourself and/or your partner; siblings; friends; nurse/doctor; other professionals; knows it from TV programme; read in a book; internet (including watching pornography); teachers.
5. Do you feel able to talk about these subjects with a child? Answers: in a very basic way; yes, quite well; no, not at all; yes, in-depth; and unsure
6. If not, why? The following options were available to choose from: my child would not understand; my child does not want to talk about it; I did not feel comfortable; I did not know how; other reasons; it would cause problems.
7. How comfortable do you feel discussing sexuality-related issues with your child? Format of the answers: no, not at all; a little; quite a lot; a lot; unsure.
8. How much have you discussed sex and relationships with your child? Format of the answers: no, not at all; a little; quite a lot; a lot; unsure.
9. Whose responsibility is it to provide sex education to people with learning disabilities? Options to choose from (more than one could be picked): parents/ families; schools, social workers; doctors/ nurses.

4.3.2.5 Big Five Inventory.

All the used tools can be found in the appendices: Big Five Inventory (Appendix 6), Perceived Stress Scale (Appendix 7), and Locus of Control (Appendix 8).

The Big Five Inventory (BFI) (John, Donahue, & Kentle, 1991**)** is based on the Big-Five framework, which is a model of personality traits with five broad, bipolar factors: openness to experiences, conscientiousness, extraversion, agreeableness, and neuroticism (Gosling, Rentfrow, & Swann, 2003). There are several questionnaires measuring these dimensions (e.g. the 60-item NEO Five-Factor Inventory NEO-FFI; Costa & McCrae, 1992) and the 44 item BFI, which is a quick measure with good psychometric properties (John, Naumann, & Soto, 2008) was used. Participants are asked to indicate to what extent they agree with a description, for example: "I am talkative". The answers are rated on a five-point scale, ranging from strongly disagree (1 point) to strongly agree (5 points). Subscale scores are created by reverse scoring specified items, summing the ratings for the items on each subscale, and dividing by the total number of items to obtain a mean score, making the potential range of scores of a minimum of 1 and maximum of 5 for each subscale (Worrell & Cross Jr, 2004). The number of questions for each Big 5 domain are as follows: openness to experiences (10 questions), conscientiousness (9), extraversion (8), agreeableness (9) and neuroticism (8). The measure has been used frequently in a wide range of research and has been translated into at least eight languages (Thalmayer, Saucier, & Eigenhuis, 2011). The tool has well-researched good psychometric properties. John, Naumann, and Soto (2008) reported that the average alpha reliability from many US and Canadian samples was above .80 and mean test-retest coefficient was .85. Validity evidence also includes substantial convergent and divergent relations with other tools measuring the Big 5 domains and the average validity correlation between BFI self-reports and three BFI reports by peers equalled .55 (John et al., 2008). The BFI is a short measure, taking approximately five minutes to complete. Moreover, the BFI items are shorter and easier to understand than, for example, the NEO-FFI (John & Srivastava, 1999).

4.3.2.6 Perceived Stress Scale.

The Perceived Stress Scale (PSS, Cohen, Kamarck, & Mermelstein, 1983) is used to assess the degree to which people perceive their lives as stressful. It consists of 14 questions and participants are asked how often they have found their lives unpredictable, uncontrollable, and overloaded in the last month, for example, "In the last month, how often have you been upset because of something that happened unexpectedly?", "In the last month, how often have you felt nervous and 'stressed'?" The scaling is as follows: 0 = Never; 1 = Almost Never; 2 = Sometimes; 3 = Fairly often; 4 = Very often. The PSS scores are obtained by reversing the scores on the seven positive items and then summing across all 14 items, meaning that the range of possible scores is 0-56. A high score indicates a high level of stress. The items are easy to understand, and the response alternatives are simple to grasp. Moreover, the questions are of a general nature and hence are relatively free of content specific to any subpopulation group. The reliability was tested using three samples and coefficient alpha reliability was .84, .85, and .86 in each of the three samples (Cohen et al., 1983). Reliability correlation coefficient tested by test-retest was .85 in a sample where participants were asked to complete the PSS after two days, and .55 for participants who were retested after six weeks (Cohen et al., 1983). The authors of the scale correlated the tool with other measures (e.g. Life Event Scores) and found that it had good concurrent and predictive validity (Cohen et al., 1983).

4.3.2.7 Locus of control.

Locus of control is a concept that refers to perceived sources of control over behaviours and events (Rotter, 1966). Currently, there are over 30 scales measuring the concept (Nowicki Jr, & Duke, 2013). One of the questionnaires measuring the locus of control is called Parental Locus of Control Scale (PLOC), which was created by Campis et al. (1986). It has been used in many studies regarding stress levels among parents of children with LD (i.e. Hassall et al., 2005). However, the decision was made to use the scale

measuring the general locus of control as the PLOC is strictly related to raising a child and I was interested in people's baseline appraisals of the controllability of the environment that are not limited to specific contexts or times. In addition, some parents in this study were responding about adult children who might have left home. Each item of the Locus of Control Scale presents a forced-choice pair of statements with one internally oriented and another externally oriented. The scale asks participants to choose one of two options about the way they see the world, for example, "In the long run, people get the respect they deserve in this world" vs. "Unfortunately, an individual's worth often passes unrecognized no matter how hard he tries." One point is given for each statement representing external control. Six of the items are filler items and 23 are scoring items meaning that the scores range from 0 to 23. A high score indicates external locus of control and low score internal. Rotter (1966) reported that the internal consistency, measured by the split half-method and Kuder Richardson coefficient was equal = .73 in both cases; therefore, it can be assessed as good. The test-retest reliability was also good, with correlation coefficient after 1-month being r = 0.72 and after 2-month period r = .55. A meta-analysis of 120 studies based on 94 samples using the scale also showed good average reliability of 0.70 (Ng, Sorensen, & Eb, 2006). Additionally, Rotter (1966) reported that the LOC scale correlated well with other methods used to assess locus of control. Its discriminant validity was indicated by the low levels of relationships with such variables as adjustment, social desirability, or need for approval, political liberalness, and intelligence. Its construct validity came from predicted differences in behaviour for individuals and involved attempts to control the environment, achievement motivation, and resistance to subtle suggestion. Overall, Rotter's Locus of Control Scale shows excellent psychometric properties supporting its reliability and validity (Wang & Lv, 2017).

4.3.3 Procedure.

The survey started with an outline of the research (see Appendix 9). Potential participants were informed of the content of the survey, the estimated time to complete (30-45 minutes), risk associated and contact details for myself and my supervisors. Potential

participants were informed of an option to take part in a prize draw (£50 M&S voucher), which involved leaving an email address. Next, participants were asked for their consent to take part, confirming that they understood the information about the research and their right to withdraw. If the consent was not given, the survey was aborted, and no further questions displayed. Following consent, participants were asked to confirm that they had a child with LD, and that they were living in the UK. Afterwards, the sociodemographic questions were asked.

Next, participants gave information about their child. This was followed by a warning about the sexual nature of the questions and advice not to complete the questionnaire in public places, as requested by the ethics panel. Afterwards, 60 questions regarding the perceived level of sexual knowledge of the children of participants were presented. This was followed by nine questions regarding parents' comfort discussing sex-related issues, who they considered being responsible for passing sexual-health knowledge to their children and views on sex education. After that, the Big Five Inventory (BFI), Locus of Control and the Perceived Stress Scale questions were introduced. At the end of the survey, participants could leave their email addresses if they wanted to be included in the prize draw.

4.3.4 Data analysis.

The data was analysed using several statistical methods: correlations, group comparisons and multiple regression.

In order to conduct Pearson's correlations, assumptions for correlations need to be checked (variables continuous, linear relationship between the variables, no significant outliers, data normally distributed). If assumptions are not met, the correlational relationship could be tested using a non-parametric test, for example, Spearman's rho, which requires only two assumptions to be met: variables at least ordinal and monotonic relationship between variables (Wilson & McLean, 2011).

Parametric tests of differences in scores of two or more groups require three assumptions to be met: the data should be interval/ratio and normally distributed, and there should be homogeneity of variance (Wilson & MacLean, 2011). When comparing averages of two samples, a *t* –test is usually run, but in the situation of the assumptions not being met, the Mann-Whitney *U* – test, which is a non- parametric equivalent of *t* – test, can be used. The Mann-Whitney *U* – test has three main assumptions: a continuous or ordinal dependent variable, independent variable being categorical with two groups and observations, which are independent. With the *U* - test, scores from two groups are combined and ranked in order from lowest to highest. If there is a difference between the two groups, then the ranks for the scores in one group should be consistently above the ranks from the other group (Wilson & MacLean, 2011).

When comparing averages of three or more groups and when assumptions have been violated, a non – parametric test needs to be used. The non- parametric equivalent of the one-way between-subjects ANOVA is the Kruskal-Wallis test. It is an extension of the Mann-Whitney *U* - test and it works in the same way and has the same assumptions that need to be met in order to run it.

In order to conduct multiple regressions, several assumptions needs to be met: the dependent variables needs to be continuous, the independent variables either continuous or categorical, the independence of observations, the linear relationships between the dependent variable and each of the independent variables, and the dependent variable and the independent variables collectively, the data needs to show homoscedasticity, no multicollinearity, no significant outliers, high leverage points or highly influential points, and the residuals (errors) approximately normally distributed.

An appropriate effect size estimate for a non-parametric test is the r- value. Cohen's guidelines for *r* are that a large effect is .5, a medium effect is .3, and a small effect is .1 (Fritz, Morris, & Richler, 2012).

As there is no formal consensus for when Bonferroni procedure should be used, even among statisticians (Perneger, 1998), I decided not to employ it. According to Rothman (1990), the theoretical basis for advocating a routine adjustment for multiple comparisons is the universal null hypothesis that chance serves as the first-order explanation for observed phenomena. In his opinion, the hypothesis undermines the basic premises of empirical research, which suggests that nature follows regular laws that may be studied through

observations. Rothman (1990) recommends that adjustments for multiple comparisons are not done because as this will lead to fewer errors of interpretation when the data are not random numbers but actual observations. What is more, adjustments for making multiple comparisons are recommended to avoid rejecting the null hypothesis. Unfortunately, reducing the type I error for null associations increases the type II error for those associations that are not null (Rothman, 1990). In addition, Perneger (1998) suggests that the Bonferroni method is concerned with the general null hypothesis (that all null hypotheses are true simultaneously), which is rarely of interest or use to researchers. Perneger (1998) also writes that the main weakness of the Bonferroni correction is that the interpretation of a finding depends on the number of other tests performed and that it was developed to aid decision making, not to assess evidence in data. Nakagawa (2004) suggests that the pressure to use the correction procedure stem from overemphasis on statistical significance (i.e., *p* values) rather than more emphasis on practical significance (i.e., effect size). Hence, an effect size is provided for each result in this study.

The data analysis started by removing incomplete responses (9) leaving a total of 83 participants. Next, as some individual answers were missing, frequencies for each question were checked to make sure that the missing values constituted less than 5% of all the responses. Once this was established, missing values were replaced with a series mean (an average of all the obtained scores for the question). Afterwards, negatively scored items from the BFI and PSS scales were recoded. Answers "unsure" from the perceived knowledge questionnaire were replaced with the mean number achieved for the question. Next, total sums for the knowledge questions, BFI, LOC and PSS were calculated. Plots were created for each data set to ensure that they followed a normal distribution. The analysis of the PLK showed presence of significant outliers. Therefore, for each instance when the PLK is used as a variable, non- parametric tests were used.

4.4 Study 2 Results

The results regarding each group of hypotheses (relationships between PLK and parental psychological factors, parental sociodemographic variables and child variables) will be presented below. Parental psychological variables in the context of this thesis refer to personality, stress levels, and locus of control. The results regarding parental views on sex communication and education and the hypotheses related to it will be presented in chapter 4.4.4.

4.4.1 Hypotheses regarding parental psychological factors.

The following hypotheses were put forward regarding the associations between parental psychological factors and the PLK:

1. There will be a positive correlation between parental extraversion, agreeableness, conscientiousness, and openness and the PLK.
2. There will be a negative correlation between parental neuroticism and the PLK.
3. There will be a negative correlation between parental stress levels and the PLK.
4. There will be a negative correlation between parental locus of control and the PLK.

The descriptive statistics for the results obtained from the participants in the questionnaires can be found in Table 16.

Table 16

Minimum and maximum values, means, and standard deviations of the PLK, Perceived Stress Scale (PSS), Big Five Inventory dimensions (Openness= Open, Conscientiousness= Cons, Extraversion= Extra, Agreeableness= Agree, Neuroticism= Neuro) and Locus of Control (LOC)

	Perceived Knowledge	PSS	LOC	Open	Cons	Extra	Agree	Neuro
N	83	83	83	83	83	83	83	83
Mean	98.43	28.13	12.72	3.61	3.83	3.28	3.95	2.98
Std. Dev	25.82	7.28	3.65	.62	.59	.74	.59	.90
Min	45.13	9	5	1.40	2.56	1.13	2.11	1.13
Max	177.00	44	21	4.90	5.00	4.63	4.89	4.75

As the assumptions necessary to conduct Pearson's correlations were not met, the correlational relationship was tested using Spearman's rho. Spearman's correlations indicated that the only association between the PLK and parental psychological variables was for neuroticism ($r_s(83) = -.33$, $p = .002$), see Table 17. Neuroticism together with its component traits of general emotionality, impulsivity, fear, and anger predisposes individuals toward negative affect (Costa & McCrae, 1980). The negative correlation between neuroticism and the PLK suggests that parents who are less fearful, anxious, and more emotionally stable see their children as being more knowledgeable. The lack of association between PLK and other parental psychological variables means that no hypotheses regarding association between parental psychological factors and the PLK were supported, except for the prediction of negative correlation between parental neuroticism and PLK, which was supported.

Table 17

Correlations (Spearman's rho) between the PLK and the Perceived Stress Scale (PSS), Big Five Inventory dimensions (Openness= Open, Conscientiousness= Cons, Extraversion= Extra, Agreeableness= Agree, Neuroticism= Neuro) and Locus of Control (LOC)

	PLK	PSS	LOC	Extra	Cons	Agree	Neuro	Open
PLK	1.00	-.11	-.01	.15	-.01	.02	-.33**	.11
PSS		1.00	.45**	-.21	-.33**	.01	.68**	-.01
LOC			1.00	-.34**	-.11	-.15	.43**	-.14
Extraversion				1.00	.28*	.39**	-.46**	.22*
Conscientiousness					1.00	.34**	-.36**	.15
Agreeableness						1.00	-.10	.19
Neuroticism							1.00	-.33**
Openness								1.00

4.4.2 Hypotheses regarding parental sociodemographic factors.

Hypotheses regarding associations between parental sociodemographic variables and the PLK for the study were as following:

1. Participants identifying with any religion will report a high PLK of their children.
2. There will be a positive correlation between parental religiosity and the PLK.
3. There will be a positive correlation between household income and the PLK.
4. There will be a positive correlation between parental education and the PLK.

The summary of answers regarding religious affiliation can be found in Table 18. Most of the participants identified themselves to be Christians, "other" or as having no religious preference. A decision was made to remove participants who responded "prefer not to say" from further analysis and combine the remaining answers into two groups "religion" (Christians plus other religions) vs "no religion". A Mann-Whitney test indicated that the PLK was greater for children of parents who affiliated with a religion (mean rank = 45.88, *Mdn* = 96.61, *N* = 45) than for those who had no religious preference (mean rank = 34.90, *Mdn* = 89.44, *N* = 36), *U* = 590.5, *p* = .04, *r* = .23. Therefore, the hypothesis that participants identifying with any religion will report higher PLK of their children, was supported.

Table 18

Mean PLK results grouped by parental religion

Religion	N	Mean PLK	Std. Deviation
Christian	38	98.77	21.73
No preference/ no religious affiliation	36	94.68	26.58
Prefer not to say	2	114.03	31.80
Other	7	111.38	39.39
Total/ average	83	98.43	25.82
Merged:			
Religion	45	100.73	25.10
No religion	36	94.68	26.50

The results regarding religiosity defined as how active people considered themselves in the practice of their religious preference can be seen in Table 19. The answer "Does not apply/ prefer not to say" was removed from further analysis. As the number of cases in the remaining answers was low, a decision was made to merge the answers "very active" and "somewhat active" into one group called "active" and the responses "not very active" and "not active" into a group called "not active."

Table 19

Mean PLK results depending on how active participants considered themselves to be in practice on their religious preference

Religiosity	N	Mean PLK	Std. Deviation
Very active	5	92.24	6.54
Somewhat active	19	98.40	22.93
Not very active	12	98.98	24.36
Not active	20	107.89	31.62
Does not apply/ prefer not to say	27	92.34	25.22
Total/ average	83	98.43	25.82
Merged:			
Active	24	97.12	20.63
Not active	32	104.55	29.03

The Mann - Whitney *U*- test was conducted to check if there were any differences in the PLK depending on how active parents considered themselves in the practice of their religious preference. The results of the *U*- test suggest that there is no difference in the PLK between children of parents who identified themselves as active (mean ranks = 28.08, *Mdn* = 95.57, *N* = 24) and those not active in practice of their religious preference (mean ranks = 28.81, *Mdn* = 94.97, *N* = 32), *U* = 374, *p* = .87. Therefore, the hypothesis that the religiosity would be associated with the PLK was not supported.

Mean PLK results depending on the household income can be seen in Table 20 (data for three participants was missing). Participants were divided into two groups; those whose

household income was either below or above £30k. The results of the *U*- test suggest that there is no difference in the PLK between parents who earn less than £30k (mean ranks = 39.29, *Mdn* = 92.59, *N* = 46) and more than £30k (mean ranks = 42.15, *Mdn* = 94.14, *N* = 34), *U* = 726, *p* = .59. Therefore, the hypothesis that the higher the household income, the higher the PLK of the child was not supported.

Table 20

Mean PLK results grouped by the household income

Income	N	Mean PLK	Std. Deviation
Less than £10k	14	101.44	39.04
£10-20k	16	102.24	27.71
£20-30k	16	93.67	20.71
£30-40k	7	102.69	30.20
More than £40k	27	97.50	18.99
Total/ average	80	98.83	26.02
Merged:			
Less than £30k	46	99.02	29.24
More than £30k	34	98.57	21.32

Table 21 presents data regarding the level of education of the participants and the mean PLK results. The participants were merged into two groups: those with GCSE's and A Levels and those with degrees and above. The PLK for participants with GCSE/ A Levels (mean ranks = 36.55, *Mdn* = 92.65, *N* = 29) and participants educated to degree level or above (mean ranks = 38.91, *Mdn* = 91.34, *N* = 46) were compared using a Mann – Whitney *U* - tests. No significant difference was found, *U* = 625, *p* = .64. Therefore, the hypothesis that the higher the level of education of the participant, the higher the PLK was not supported.

Table 21

Mean PLK results grouped by the level of education

Education	N	Mean PLK	Std. Deviation
Apprenticeship	1	79.87	-
GCSE	11	93.92	31.43
A Levels or equivalent	18	104.54	30.84
Degree or above	46	98.62	24.29
Other qualifications	7	91.17	8.94
Total/ average	83	98.43	25.82
Merged:			
GCSE & A Levels	29	100.51	30.95
Degree and above	46	98.62	24.29

4.4.3 Hypotheses regarding children's factors.

There were three hypotheses regarding associations between the children's variables and the PLK:

1. The higher the level of functioning of the child with LD, the higher the PLK.
2. Parents of children, who received formal sex education, will report a high PLK.
3. Parents will report that their daughters present higher PLK than sons.

The level of functioning of the child was checked by two questions: one about the level of LD and the second one regarding the amount of required support. The first hypothesis was tested using answers from both questions.

The means and standard deviations of individuals with different levels of functioning can be seen in Table 22. A Kruskal-Wallis test showed that there was no statistically significant difference in the PLK score between children with the different levels of functioning $\chi 2(2) = 3.89$, $p = .14$, with a mean rank PLK score of 53.07 for mild LD, 40.98 for moderate LD and 37.46 for severe LD, however the trend was in the predicted direction i.e. the mean PLK for those with mild LD was higher than for those with moderate and severe LD.

Table 22

Means and standard deviations in perceived level of knowledge depending on the level of functioning

Level of functioning	N	Mean PLK	Std. Deviation
mild	14	115.19	34.39
moderate	45	97.43	25.62
severe	24	90.53	14.69
Total/ average	83	98.43	25.82

Table 23 presents the means and standard deviations of the perceived knowledge results depending on the level of support required by the disabled child. As the groups were relatively small, a decision was made to collapse the answers "no or occasional support", "needs a few hours of support a day" and "requires support, but less than a few hours a day" and compare it with the results related with the answer "requires support for most activities." The results of the Mann- Whitney *U*- test suggest that there is a statistically significant difference in the PLK between children who required support for most activities (mean ranks = 33.15, *Mdn* = 89.75, *N* = 46) and those who required no support or a few or less hours of support a day (mean ranks = 53, *Mdn* = 101.60, *N* = 37), $U = 444$, $p < .001$, $r = .41$. Children

who required support for most activities were assessed by their parents to be less knowledgeable than those, who required no support or a few or less hours of support a day.

Table 23

Means and standard deviations of the perceived level of knowledge of the individuals with learning disabilities depending on the level of support required

Level of support	N	Mean PLK	Std. Deviation
Requires support for most activities	46	88.21	15.23
Needs a few hours of support a day	22	101.26	22.51
Requires support, but less than a few hours a day	12	127.15	35.51
No or occasional support	3	119.50	41.99
Total/ average	83	98.43	25.82
Merged:			
Require support for most activities	46	88.21	15.23
No support or a few or less hours of support a day	37	101.40	30.50

As the results of the comparisons between different levels of functioning of the child depended on the type of question asked, a conclusion regarding the hypothesis cannot be made.

Table 24 presents differences in the means of the PLK depending on the level of sex education received. As the numbers of participants in each group were small and varied, the answers were grouped into two categories: those who had received an education ("quite a lot" and "a lot") and those who had had no or little education. The answer "unsure" was removed from further analysis.

Table 24

Means and standard deviations in perceived level of knowledge of the individuals with learning disabilities depending on the received education

Level of education	N	Mean PLK	Std. Deviation
no, not at all	16	91.59	6.83
a little	40	89.03	18.03
quite a lot	18	117.82	33.96
a lot	8	117.71	32.41
unsure	1	80.40	-
Total/ average	83	98.43	25.82
Merged:			
Education	26	117.78	32.84
No or little education	56	89.76	15.64

The results of the Mann- Whitney *U*- test indicated the PLK of children who had no or little sex education (mean ranks = 34.04, *Mdn* = 91.08, *N* = 56) was statistically significantly lower than those who received "quite a lot" and "a lot" education (mean ranks =

57.58, *Mdn* = 104.60, *N* = 26), *U* = 310, *p* < .001, *r* = .46. This finding supports the hypothesis that receiving sex education is related to higher levels of perceived knowledge.

To test the last hypothesis, the Mann - Whitney *U* - test was conducted to check if there was a difference in the way parents assessed the PLK of their sons (*N* = 54, *M* = 97.72, *SD* = 25.46) and daughters (*N* = 29, *M* = 99.75, *SD* = 26.90). The results of the Mann – Whitney *U*- test suggest that there is no difference in the perceived knowledge between women (mean rank = 42.65, *Mdn* = 92.11, *N* = 29) and men (mean rank = 39.41, *Mdn* = 93.07, *N* = 54), *U* = 773.5, *p* = .55. Therefore, the hypothesis was not supported.

4.4.4 Views on sex- related communication and their impact on the knowledge of the children.

This section will outline answers given to the nine questions exploring parental views regarding the sex education of their children and people with LD in general. A summary of the answers to five of the questions with the same, Likert type format of answers are presented in Table 25. Next, answers to remaining questions are presented. Following the summary of the answers, analysis of the relationship between parental assessment of their comfort, ability and quantity of sex-related discussion and PLK will be described to test the hypothesis: There will be statistically significant differences on the PLK by the level of quantity, confidence and comfort of parent- child sex-related communication.

Table 25

The results regarding parental views on sex education and sex-related communication

Question	No, not at all	N	A little	N	Quite a lot	N	A lot	N	Unsure	N	Total
Has your child had any form of sex education?	19.28 %	16	48.19%	40	21.69%	18	9.64%	8	1.20%	1	83
Do you think that more sex education is needed for people with learning disabilities?	3.66%	3	23.17%	19	28.05%	23	43.90%	36	1.22%	1	82
Do you think your child would like to know more about sexuality?	26.83 %	22	24.39%	20	13.41%	11	18.29%	15	17.07%	14	82
How comfortable do you feel discussing sexuality related issues with your child?	7.23%	6	31.33%	26	28.92%	24	32.53%	27	0.00%	0	83
How much have you discussed sex and relationships matters with your child?	14.46 %	12	49.40%	41	19.28%	16	16.87%	14	0.00%	0	83

Apart from the questions listed in the Table 25, participants were also asked who had given their child information on sex. More than one option could be chosen. Nearly thirty percent (29.91%) had provided the information themselves and/or their partner did, and over one third (35.27%) replied that teachers did it. Other responses included: friends (6.25%), knows from a TV programme (5.80%), read it in a book/magazine (4.91%), siblings (4.91%), doctor/nurse (3.57%) and other professional (5.36%). Next, participants were asked whose responsibility it was to provide sex education to people with LD. Again, more than one option could be chosen. An answer "parents/ family" was chosen by 34.38% of the participants, 30.36% responded that it was the "schools' responsibility", 14.73% said it was down to "support workers/ personal assistants", 11.61% believed it was up to "doctors/ nurses" and 6.70% "social workers."

When asked: "Do you feel able to talk about these subjects with your child?" nearly half of the participants (39, 47%) responded that in a "in a very basic way," 22 participants (26.51%) replied "yes, quite well," 10 and 11 participants respectively said "no, not at all" and "yes, in-depth." One person was unsure. The next question asked for the reason for not feeling able to discuss sex with the children. Thirty-nine participants responded. An answer "my child would not understand" was chosen the most frequently (18, 46%), eight participants replied "my child does not want to talk about it" (20%) and four each replied that they "did not feel comfortable," "did not know how" and "other" reasons (10% each). One person stated that "it would cause problems." The result was unexpected as in previous studies parents reported lack of support and knowledge as the main reasons for not discussing sex with their disabled children (e.g. Garbutt, 2008) and not the child's abilities.

Group comparisons were run to see if different views regarding sex education and feeling comfortable and competent to discuss sex-related issues had an impact on the perceived level of knowledge of the child. As previously, a non- parametric test was used due to presence of outliers in the PLK. Responses to the question "Do you feel able to talk about these subjects with your child?" (see Table 26), were collapsed into two categories: not feeling able to discuss sex ("not at all" and "in a very basic way") and those who felt that they could do it ("yes, quite well" and "yes, in-depth"). The answer "unsure" was removed from the analysis. The results of the Mann- Whitney *U*- test suggest that the PLK was greater for parents who reported feeling able to discuss sex and relationships (mean ranks = 56.15,

Mdn = 101.60, *N* = 33) than those who did not feel able to do so (mean ranks = 31.63, *Mdn* = 89.26, *N* = 49), *U* = 325, *p* < .001, *r* = .50.

Table 26

Means and standard deviations in perceived level of knowledge of the individuals with learning disabilities depending on the parental assessment of their ability to discuss sex topics

Ability to discuss sex	N	Mean	Std. Deviation
No, not at all	10	83.90	14.16
In a very basic way	39	88.22	14.40
Unsure	1	99.24	-
Yes, quite well	22	110.19	27.40
Yes, in-depth	11	124.23	35.61
Total/ average	83	98.43	25.82
Merged:			
Not able	49	87.34	14.32
Able	33	114.87	30.57

When it comes to parental comfort to discuss sex-related issues with their child and its impact on the means and standard deviation of the PLK results, see Table 27. Again, the responses were grouped into two categories: those who reported not feeling comfortable discussing sex with their child ("not at all" and "a little") and participants who felt comfortable ("quite a lot" and "a lot"). The results of the Mann- Whitney *U*- test indicated that there was a statistically significant difference in the PLK of children of parents who reported feeling comfortable discussing sex-related topics (mean ranks = 48.00, *Mdn* = 95.35, *N* = 51) and those who did not feel comfortable (mean ranks = 32.44, *Mdn* = 90.15, *N* = 32), *U* = 510, *p* = .004, *r* = .31, with higher PLK of children whose parents conversed with them about sex with more comfort.

Table 27

Means and standard deviations of the perceived level of knowledge of the individuals with learning disabilities depending on the parental assessment of their comfort to discuss sex-related topics

Level of comfort	N	Mean PLK	Std. Deviation
Not at all	6	88.26	7.42
A little	26	86.19	17.60
Quite a lot	24	99.82	22.40
A lot	27	111.24	31.71
Total/ average	83	98.43	25.82
Merged:			
Not comfortable	32	86.58	16.10
Comfortable	51	105.86	28.05

Parents were also asked how much they have discussed sex-related topics with their children. The mean and standard deviations of the knowledge results depending on the amount of the discussion can be seen in Table 28. As the numbers of the responses in each group were not large, a decision was made to collapse them into two groups: "no or little discussion" ("not at all" and "a little") and "a lot of discussion" ("quite a lot" and "a lot"). The Mann- Whitney *U*- test was run to see if there was a statistically significant difference between the groups. The results of the Mann- Whitney *U*- test suggested that there was a statistically significant difference in the PLK, with children of parents who discussed sex and relationships "a lot" and "quite a lot" being assessed by their parents as more knowledgeable (mean ranks = 54.50, *Mdn* = 101.01, *N* = 30) comparing to those who did not discuss or discussed it a little (mean ranks = 34.92, *Mdn* = 91.12, *N* = 53), *U* = 420, $p < .001$, *r* = .39.

Table 28

Means and standard deviations of the perceived level of knowledge of the individuals with learning disabilities depending on the level of discussion

How much discussion	N	Mean PLK	Std. Deviation
Not at all	12	90.17	6.16
A little	41	90.04	20.96
Quite a lot	16	104.26	26.18
A lot	14	123.42	32.13
Total/ average	83	98.43	25.82
Merged:			
No or little discussion	53	90.07	18.60
A lot of discussion	30	113.20	30.20

A simultaneous multiple regression was run to predict PLK from the amount of sex-related discussion, reported feelings of comfort and ability to conduct such a conversation to see if the variables can help to predict scores on the PLK and which one of these factors played the most important role. First, tests were run in order to check that the data met all the assumptions required to run a multiple regression. As significant outliers and influential points were detected (tested by the Cook's Distance), those results were removed from further analysis (9 cases). The results of the regression indicated that variables related to the sex- related discussion statistically significantly predicted the PLK (R^2 = .19, *F* (3, 70) = 5.69, *p* =.002). Only feeling able to discuss sex added statistically significantly to the prediction, *p* = .021.

4.4.5 Best and least known areas.

A common theme for all the studies forming this thesis is the assessment of the best and least known areas when it comes to the sexual health knowledge of people with LD. The amended SexKen knowledge subscales, number of knowledge questions in each of them, maximum and mean scores and percentage of correct answers are presented in Table 29.

Table 29

Amended SexKen subscales, number of knowledge questions, maximum and mean scores and percentage of correct scores

Sex-Ken subscale	Number of knowledge questions	Mean score of participants	Maximum score possible	Percentage of positive answers
Body part identification	9	21.1	27	78%
Marriage	1	2.33	3	76%
Homosexuality	1	1.85	3	61%
Menstruation	4	7.27	12	60%
Sex	1	1.71	3	57%
Pregnancy, abortion, and childbirth	11	18.2	33	55%
Sexual interaction	17	26	51	51%
Contraception	5	6.28	15	42%
Masturbation	3	3.72	9	41%
Sexually transmitted diseases	8	9.72	24	40%

As with the assessment of the best and least known areas of participants in Study 1, if the percentage of the mean to maximum scores was less or equal 33%, the knowledge was described as poor, higher than 33%, but lower than 66% -medium and equal to or higher than 66% as good.

Two topics where the knowledge can be described as good are marriage and body parts identification. According to the parents, their children with LD possessed the least knowledge about contraception, masturbation, and sexually transmitted diseases. Further

discussion and comparisons of the best and least known areas as reported by participants from all three studies, can be found in Chapter 6.1.1.

4.5 Summary and Discussion

Below is the list of all hypotheses for the study with annotation whether they were supported:

I. Parental psychological factors

1. There will be a positive correlation between parental extraversion, agreeableness, conscientiousness, and openness and the PLK. - **not supported**

2. There will be a negative correlation between parental neuroticism and the PLK. - **supported**

3. There will be a negative correlation between parental stress levels and the PLK. – **not supported**

4. There will be a negative correlation between parental locus of control and the PLK. – **not supported**

5. There will be statistically significant differences on the PLK by the level of quantity, confidence and comfort of parent- child sex-related communication. - **supported**

II. Parental sociodemographic variables

7. Participants identifying with any religion will report higher PLK of their children. - **supported**

8. There will be a positive correlation between parental religious activity and PLK. - **not supported**

9. There will be a positive correlation between household income and PLK. - **not supported**

10. There will be a positive correlation between parental education and PLK. - **not supported**

III. Children's variables

12. The higher the level of functioning of the child with LD, the higher the PLK. - **not supported for the level of functioning defined by the level of disability (although trend**

in the right direction) but supported when functioning categorised according to support needs.

13. Parents of children, who received formal sex education will report higher PLK. - **supported**

14. Parents will report that their daughters present higher PLK than sons. – **not supported**

The study was unique in the sense that the parental perception of the sexual health knowledge of their children with LD and factors associated with the perception has not been investigated previously. Therefore, comparisons of the results with other studies are not possible. The only previous study that compared actual knowledge of people with LD with the perception of their carers (paid, not family) was Szollos and McCabe (1995). They found that care staff consistently overestimated the responses of their clients, whom they perceived to be more knowledgeable and experienced, have a greater need to know, than was indicated by the clients themselves (Szollos & McCabe, 1995). The authors did not provide an explanation of this phenomenon.

Parental stress, locus of control and personality dimensions (openness, conscientiousness, agreeableness, and extraversion), apart from neuroticism, do not appear to be associated with the PLK. The negative correlation between neuroticism and the PLK suggests that parents who are less anxious and more emotionally stable see their children as being more knowledgeable. This was predicted as high levels of neuroticism was shown to be related to less competent parenting (Metsäpelto & Pulkkinen, 2003). In addition, Metsäpelto and Pulkkinen (2003) also found that mothers' low neuroticism levels were associated with high nurturance and high parental knowledge (measured as parents' awareness of the child's friends, whereabouts, and activities, the parent knowing the child's daily schedule, the child's interests and whereabouts, and finding out where and with whom the child was).

Parents who reported frequent discussions about sex-related topics reported a higher PLK of their children. Family carers who felt comfortable and able discussing sex-related topics reported a higher PLK than those who did not. Results of the multiple regression suggest that feeling able to communicate about sex and sexual relationships explains nearly 20% of variation on the PLK. This is in line with previous research, which showed that parental perception of their knowledge, confidence and level of comfort were important factors playing a role in the parent-child sex-related communication (DiIorio et al., 2000;

DiIorio et al., 2003; Guilamo-Ramos et al., 2008; Jerman & Constantine, 2010). Durex et al. (2010) reported that 62% of parents of non-disabled children did not feel trained and confident talking about sex and relationships. When asked if they felt able to talk about sex with their children, nearly half of the participants (39, 47%) in my study responded that in a "in a very basic way," and nearly 40% that they felt able to do it "quite well and "in-depth." When it comes to the comfort of having the discussion, 64% of the participants in my sample replied that they were "quite" comfortable and "a lot" comfortable. Both results are higher than those coming from the general population (i.e. Durex et al., 2010), which is surprising considering the lack of support and knowledge reported by parents of children with disabilities in previous studies (e.g. Garbutt, 2008). In addition, parents in my sample mentioned their children's lack of understanding as the main reason for not being able to discuss sex and relationships, rather than their own limitations (i.e., lack of knowledge, embarrassment).

In practical terms, it can be suggested that interventions, such as workshops for parents, aimed at increasing abilities and comfort of mothers and fathers in the field of sex and relationships, could lead to increased parent-child sex-related communication and as a result to a better sexual health knowledge of a child. This is also supported by the fact that the results of my study show that the reason for low perceived knowledge of the children was not due to inherent factors in the parents like personality and therefore could be changed through training.

Having religious beliefs was shown to be related to the PLK. No relationship was found between religious activity (religiosity) and the PLK. These results are similar to those found by researchers in previous studies, however the impact of religion and religiosity were only measured in respect to parent- child communication and not knowledge.

Parental education and the household income were not linked to PLK in this study. This is a somewhat surprising finding as research conducted by Sprecher et al. (2008) amongst non-disabled University students showed that the higher the participant's social class, the more sex education reported from their parents. However, the result could be due to the fact that the sample was not very diverse. Participants in the sample were better educated and reported higher levels of income than the general population in England. The reported income of 75% of the participants in the sample was higher than England's national average. The majority of the participants (55.42%) who took part in my survey were educated to

"degree or above" level, whilst in the general population (England and Wales only), according to the 2011 Census, the rate of people with degree and above is 27.2% (Office for National Statistics, 2011).

The link between the level of functioning of the child and PLK is not clear and it depended on the way in which the level of functioning was categorised. The level of functioning was assessed by two questions: one about the level of LD and the second one regarding the amount of support required. The hypothesis regarding it was tested using answers from both questions. No statistically significant difference in the PLK score was found between children with the different levels of functioning categorised by the level of LD, but the results of the *U*- test suggest that there was a statistically significant difference in the PLK between children who required support for most activities and those who required a few or less hours of support a day, with children, who required less support being assessed by their parents as more knowledgeable. The correlation between the knowledge scores and IQ was observed in Study 1. The association between the level of functioning and the results of the knowledge questionnaires was shown in several previous studies as well (e.g. Konstantareas & Lunsky, 1997). The level of disability is not necessarily linked to the level of support required. The support need can be affected by the presence of challenging or problematic behaviour, for example, problems with sleep or incontinence. In addition, the results of the group comparisons of the PLK between children with mild, moderate or severe disabilities showed the expected trend i.e. individuals with more severe LD appearing to be less knowledgeable, but the results did not reach statistical significance levels.

Having sex and relationships education seems to have an effect on the knowledge regarding sexuality. Parents of children who participated in SRE assessed them as having higher PLK than those who had little or no sex education. Participants in Study 1, who reported having some form of a sex education also scored significantly higher on the SexKen questionnaire than those, who never had any education. The result was predicted as the positive impact of sex education on knowledge was shown in previous research as well (e.g. Lindsay et al., 1992; Penny & Chataway, 1982). This finding confirms the need for compulsory SRE for all, including children and adults with LD, especially those with more severe disabilities.

The study found no difference in the way parents assessed the PLK of their sons and daughters. This result is unexpected considering that review of literature regarding

communication between parents and children in the general population consistently showed that mothers communicated more with their daughters (e.g. DiIorio et al., 2003) and most of the participants in the study were females. The potential explanation could be that when it comes to children with disabilities, other factors such as the level of functioning or communication abilities, play a more important role than the gender of the child. The results of Study 1 from this thesis also showed no difference in knowledge between females and males.

When it comes to the sources of sex- related information of people with LD (more than one option could be chosen), two thirds of parents reported that they provided the information themselves or that the teachers did it. When asked whose responsibility it was to provide sex education to people with LD, similar percentages pointed to 'Parents/ Family' (34.38%) and school (30.36%). In the research by Garbutt (2008), the majority of the parents of children with LD stated that they felt they were the primary educators for their children; however, they believed that the education should not be down to one person and more input from professionals was expected. In the survey conducted by Durex et al. (2010) amongst general public, 84% of parents believed that sex education should be delivered by school and home and collaboration between schools and parents should be the top priority.

Two topics where the perceived knowledge can be described as good are marriage and body parts identification. The results of this study suggest that parents believe that their children with LD have the least knowledge about contraception, masturbation, and sexually transmitted diseases. This is in line with findings from a literature review conducted by myself (Borawska-Charko et al., 2016), which suggested that the topic of body parts and physical characteristics appeared to be the best understood, with birth control methods and STDs being the least understood by individuals with LD.

4.6 Limitations of the Study and Recommendations

The findings of the current study support the need for sex education for people with LD and the involvement of parents in the sexual education of their children, and they point to the need for the development of programs to facilitate parent-child communication and the education of the parents to increase their feelings of competence and comfort. Almost 80% of school leaders who took part in the survey organised by Durex et al. (2010), expressed an opinion that parents should receive help and support in talking to their children about sex in order to make sure that all learners possessed sufficient and appropriate knowledge.

This study has several limitations. First, clinical diagnosis of LD in the current study was based on the parents' report only. As with all convenience samples, the results are not representative of the whole population and have to be treated with caution. The current sample was composed, predominately, of well-educated, reasonably wealthy married women and this limits the generalisability of the findings. In addition, the inclusion criteria for the study did not specify age of the child resulting in a wide range of ages (4-37 years). On reflection, the minimum age of 13 should have been introduced in order to make comparisons with participants from the Study 1 easier and to control for potential effect of age on knowledge. As 31 of the children of the participants were younger than 13 years old, it was impossible not to include them in the analysis. However, there was no correlation between the age of the children of the participants in the sample and the PLK (r (83) = .19, p = .08). Results of Study 1 also suggested that there was no association between the age and the knowledge of the participants. It can be speculated that when it comes to individuals with LD, mental age plays more important role on the level of knowledge than the chronological age. Therefore, the fact that some of the children of the participants were very young, did not appear to have an impact on the final results.

Moreover, it can be speculated that the parents who agreed to take part in a survey regarding sexuality present more positive attitudes towards sex and felt more comfortable answering questions related to sex. For this reason, parents might have communicated more about sex-related issues with their children, which could have led to a greater knowledge displayed by the children. Therefore, the perception of their children's knowledge may not be representative. In previous research, discomfort and embarrassment were mentioned by carers as barriers to parent-child sex-related discussion (DiIorio et al., 2003). In my study, most of the participants (64%) stated that they felt comfortable discussing sex with their children, and the parent-child discussion about sex related topics was related to PLK.

When it comes to the statistical methods used for the analysis of the data, mainly non-parametric tests were used. Non – parametric tests are less powerful. Therefore, some differences between the groups might not have been detected due to the method of analysis used, as well as the size of the sample.

Finally, due to exploratory nature of the study, the research provided some insightful information, but cannot be generalisable to the population at large.

5. Chapter Five

Study 3- Views and Experiences of Teachers Providing Sex Education to People with LD

5.1 Overview

Results of Study 1 and 2 showed that the knowledge of people with LD is characterised by gaps and misunderstandings in many areas. Whilst the knowledge about body parts and marriage appears to be good, many people are not aware of STDs and contraception. This is especially concerning considering that many people with LD are sexually active. Results from Study 1 showed that 37% of participants had had sexual experiences and over a half experienced hugging with no clothes on. Results from both studies showed that participation in SRE was related to sexual health knowledge. McDaniels and Fleming (2016) conducted a literature review to examine the effectiveness of the sexual education curricula for people with LD. They concluded that as a result of inadequate sexual education, individuals with LD were at greater risk of sexual abuse, STDs and misinformation. Hence, it is crucial that people with LD receive a good quality sex and relationship education (SRE) that will equip them with the knowledge and skills required to be safe.

Thirty percent of parents who took part in Study 2 reported that teachers should be a primary source of sex-related information for their children. This might be especially important for those parents, who do not feel comfortable discussing sex- related topics with their children and 38% of participants from Study 2 did not feel comfortable or felt comfortable “a little” having such a discussion. However, in previous research, teachers delivering SRE to people with LD mentioned inadequate training or professional preparation (Howard-Barr, Rienzo, Morgan- Pigg, & James, 2005; Wright, 2011). An additional challenge recounted by staff delivering sex education in several studies (Lafferty et al., 2012; Wilkenfeld & Ballan, 2011), was a lack of resources. Special education teachers also reported feeling anxious or ambivalent about the topic (Rohleder, 2010; Wilkenfeld & Ballan, 2011) and lack of clarity regarding their role and responsibilities (Howard-Barr et al., 2005; Wilkenfeld & Ballan, 2011). Lack of parental and administrative support was also mentioned as a barrier when delivering SRE to people with LD (Howard-Barr et al., 2005).

Feeling well prepared and supported to teach the subject is important, as association between teacher’s knowledge, comfort with the subject matter and the likelihood that the knowledge will be passed on to students and be better perceived by the students was shown in

previous studies that involved SRE teachers working in mainstream schools in the USA (Hamilton & Levenson- Gingiss, 1993; Levenson-Gingiss & Hamilton, 1989). Therefore, we need to know more about the challenges teachers are facing, how educators try to overcome them, and what they see as the priorities of their work in order to understand what help might be required. This study investigated what difficulties teachers encountered when delivering sex and relationships education to people with LD, how did they believed it was best to overcome them and what teachers hoped that student would know at the end of the training. In order to gain insight into the participants' experiences, qualitative methods of data collection and analysis were adopted.

The study also had additional research questions. As with Studies 1 and 2, I was interested in the levels of sexual health knowledge of people with LD, the best and least known topics related to human sexuality and students' relational and sexual experiences. This meant that the thesis approached the issue of sexual health knowledge and experiences of people with LD from three different perspectives. Such a tactic made this research novel and gave a chance to better assess the knowledge and identify barriers that people with LD face when it comes to learning about sex-related topics and forming relationships. It also provided an opportunity to compare the three viewpoints. Another aspect that makes this study unique is the fact that, as outlined above, several studies concentrated on difficulties encountered by teachers in their work, but none of them focused in depth on recommendations how to avoid or minimise the issues. This seems particularly important when the goal of research is to influence practice, which I hope my research will do.

5.2 Method

The aim of the study was to investigate experiences and views of teachers and educators delivering sex and relationship education to people with LD. The objective of the study was to gain insight into the process of teaching, the difficulties encountered, and how teachers respond to these.

Three overarching research questions guided this study:

1. What challenges are teachers and educators facing when delivering SRE to people with LD?
2. How do teachers and educators respond to the challenges?
3. What do teachers and educators see as the priorities of their work?

The additional research questions were the following: what do teachers think about the levels of knowledge of people with LD regarding relationships and sex? What experiences, hopes and needs when it comes to relationships do their students have?

5.2.1 Participants.

Fifteen teachers/educators working with people with LD were interviewed. All participants had experience of delivering sex education to people with LD, either as a sole topic or as a part of Personal, Social and Health Education (PSHE). That was the only inclusion criterion for the study. One educator was retired and one had moved from teaching onto developing resources for sex education for people with LD and was no longer personally delivering sex education. The remaining 13 participants were actively involved in delivering sex education at the time of the interview.

Ten participants were teachers working in special schools and five were educators working for voluntary organisations providing support/education/ advocacy services for people with LD. Two people lived and worked in New Zealand, one worked in Wales (retired at the time of the interview) and the rest worked in special education establishments or charities in East Anglia. Five men and 10 women took part in the study. No further demographic data or questions about training or time in post were gathered to ensure the anonymity of the participants. All information that could be used to potentially identify the participants, such as the name of the school or location, was not transcribed. Please note, that two terms are used in the thesis- teachers (T), which refers to people working in schools, teaching SRE as the sole subject or part of PSHE, and educators (E) with refers to people employed by charities/ other organisations, delivering sex and education workshops and training.

5.2.1.1 Recruitment.

Participants were recruited via an advertisement on a forum for people with LD, their parents and professionals working with them (www.choiceforum.org), emails sent to local charities working with people with LD or by personal recommendation. In addition, emails were sent to 28 special education schools in Cambridgeshire, Essex, Suffolk, and Hertfordshire asking them to forward my invitation to participate in the study to sex education/ Personal, Social and Health Education (PSHE) teachers. I also contacted the PSHE association with a request for help with recruitment and they sent emails on my behalf to 43 people who had attended their training aimed at people delivering the PSHE in special

schools. Brief information about the research was sent to potential participants to assist them in making a decision about participation. All participants contacted me by email to express their willingness to take part in the study. Details for meetings were then arranged by emails as well.

5.2.3 Interview schedule.

The semi-structured interview questions (see Appendix 10 for interview schedule) were created for this study with the research questions in mind. Eighteen questions were grouped into five blocks. The first one contained general questions about the interviewees' experiences and these questions were aimed at building up a rapport (e,g, "What has your experience [of delivering SRE] been like?) The next set of questions were regarding the process of teaching (e.g. "What do you find the most difficult or uncomfortable to talk about?"). The following section covered questions about the perceived levels of knowledge of the students, factors affecting them, the best and least known topics and the most important areas, in teachers' opinion (e.g. "Which areas do participants have best knowledge of?, What factors affect their levels of knowledge? What do you think they need to know? What are the most important areas in your opinion?") Next, questions about students' sexual experiences, hopes and needs were raised (e.g. "What hopes/needs do they have when it comes to relationships?"). Finally, teachers were asked about parental attitudes and reactions to their children's participation in sex and relationship education (e.g. "How do parents generally feel about their children taking part in sex education sessions?").

Semi-structured interviews are widely used in qualitative research. In contrast to a structured interview, they do not require the following of a rigorous set of questions but allow new ideas to be brought up during the interview as a result of what the interviewee says. The interviewer in a semi-structured interview generally has a framework of themes to be explored and an interview guide based on that, which is an informal grouping of topics and questions, including prompt questions that the interviewer can ask in different ways for different participants. Interviewers can tailor their questions to the interview context/ situation and to the people they are interviewing and can use probing to explore topics which are of interest to them in more depth (Wilson & MacLean, 2011).

5.2.3 Procedure.

At the beginning of each interview information about the purpose and scope as well as a brief outline of the whole project and consent forms were given or sent to the participants

(Appendix 11) and explained verbally. Participants were given the opportunity to ask questions before signing or giving verbal informed consent. Everyone was given or sent a form to withdraw from the research and was informed that they could do so at any point during or after the interview. Nobody retracted their consent or stopped the interview.

The interviews lasted between 30 to 55 minutes. Eleven interviews were conducted face to face and four using internet communication via Skype. All meetings completed in person took place in the schools or organisations where the participants worked.

All interviews were audio recorded. Audiotaping offered me the opportunity to capture the participants' words verbatim. Where interviews were conducted via internet communication, recordings included verbal consent to taking part in the research. Otherwise, only the participants' answers were recorded. Two audio devices were used, as insurance should one of the devices malfunction. All participants gave consent to the audio recording the interviews. The devices were placed out of sight to reduce any feelings of self-consciousness/ discomfort.

5.2.4 Data analysis.

There are two sections of the results. One is a framework analysis and the other is an overview of the responses question by question. Description of the framework analysis process will be presented first, followed by the findings of the analysis. Next, the summary of the answers will be outlined.

The framework method belongs to a broad family of analysis methods referred to as thematic analysis or qualitative content analysis (Gale, Heath, Cameron, Rashid, & Redwood, 2013). Framework analysis was developed by Ritchie and Spencer (1994). According to them, framework analysis can be used to aim defining concepts, mapping the range, nature and dynamics of phenomena, creating typologies, finding associations, seeking explanations and developing new ideas. Framework analysis is characterised by the following key features:

- Grounded or generative: it is heavily based in, and driven by, the original accounts and observations of the people it is about.
- Dynamic: it is open to change, addition and amendment throughout the analytic process.

- Systematic: it allows methodical treatment of all similar units of analysis.
- Comprehensive: it allows a full, and not partial or selective, review of the material collected.
- Enables easy retrieval: it allows access to, and retrieval of, the original textual material.
- Allows between- and within-case analysis: it enables comparisons between, and associations within, cases to be made.
- Accessible to others: the analytic process, and the interpretations derived from it, can be viewed and judged by people other than the primary analyst (Ritchie & Spencer, 1994, p. 176).

Another advantage of the framework analysis is the fact that it could be guided by a priori ideas as well as themes that emerge from the data (Ritchie & Spencer, 1994). It was developed for addressing specific questions and in that sense can be seen as an applied research approach that is useful for informing both policy and practice (Ward, Furber, Tierney, & Swallow, 2013), which this study is aiming to achieve. The method is commonly used for the analysis of semi-structured interview transcripts where the data is not heterogenous (Gale et al., 2013).

There are five stages of framework analysis suggested by Ritchie and Spencer (1994): familiarization; identifying a framework; indexing; charting; and mapping and interpretation. When conducting the analysis, steps and advice outlined by Parkinson, Eatough, Holmes, Stapley, and Midgley (2016) and Ward et al. (2013) in their articles using worked examples were followed. In addition, the process of coding, frame working and identifying themes was discussed with the thesis supervisors on regular basis. The first supervisor has an extensive knowledge and experience of using qualitative methods.

I. Familiarising yourself with the data.

Ritchie and Spencer (1994) describe this stage as “immersion in the data” (p. 179). This can be achieved by listening to the tapes, reading transcripts and notes taken at the time the interviews were conducted. All interviews were conducted and transcribed by me, which gave me the opportunity to familiarise myself with the data. A sample of recordings with the

transcripts of them, were also reviewed by the supervisors. Based on that, feedback regarding conducting the interviews was also given.

When transcribing, reading and re-reading the transcripts, I highlighted sentences or sections where interviewees were describing their experiences.

II. Identifying a framework.

During this stage the researchers should attempt to identify key issues, concepts and themes (Ritchie & Spencer, 1994). The framework can be based on a priori ideas, but also issues raised by the interviewees. This was the case during my analysis. Based on previous research, it was predicted that the responders would mention challenges they encounter during their work, which was observed in my transcripts as well. However, ways of overcoming difficulties were also mentioned frequently. These two themes (challenges and how to overcome them) did form a framework for further analysis.

III. Indexing.

Indexing is described by Ritchie and Spencer (1994) as process whereby the thematic framework or index is systematically applied to the data. In this stage, all transcripts are read and annotated. I did this in two phases. Firstly, I exported all verbatim transcripts to NVivo software, which helps to code, organise and analyse non-numerical data. The software allows us to classify, sort and arrange information and to examine relationships in the data. Whilst re-reading the transcripts, significant passages were indexed in NVivo. Initially, 26 indexes were generated after the analysis. The index could be a word, sentence or a paragraph that captured the principal content and essence.

After applying the framework to the indexes, it became apparent that not all of the indexes matched the original two themes. Interviewees frequently mentioned topics and skills that they hoped to teach their students. A big focus was also placed on the subject of safeguarding pupils. Several teachers and educators also discussed the fact that their students hoped to form relationships, not only in the present time, but also in the future. Some indexes did not fit any of the themes and were categorised under ‘other’ section. This led to 6 themes and sub-themes (see Table 30).

Table 30

Themes and sub-themes generated during data analysis, including number of participants who discussed the themes and number of instances when it was mentioned (references)

Themes and subthemes	Number of participants	References
1. Challenges difficulties in teaching		
General difficulties	12	42
Black and white thinking	5	6
Caution awareness of background, past experiences	8	14
Changing population	1	1
Cognitive abilities	6	12
Heterogeneous groups	10	21
Homophobia	6	9
Knowing mechanics not emotions	2	5
Negative parental attitudes	10	38
Negative stuff	1	1
Prioritising	5	11
Puberty and anxiety	3	5
What horrifies students	7	15
2. How to overcome difficulties		
Continuity of education	1	2
Developing social life and skills	6	12
Good practice	14	95
Positive parental attitudes	10	20
Repetition	7	12
Skills not knowledge	2	5
Starting early	2	4
3. What students need to know		
Awareness of emotions	3	5
Internet safety	5	7
knowing what's right and wrong	8	14
Making choices	8	15
Need for knowledge	7	13
Positive attitudes towards LGBT	6	8
Rights	11	23
Sexuality as a natural need	5	7
4. Need to be in a relationship	11	22
5. Safeguarding	13	44
6. Other	7	12

IV. Charting.

The purpose of this stage is to organise the data. It involves summarising and allocating the indexed data for each theme and organising summaries in the chart form

including supporting quotes from the transcripts (Parkinson et al., 2016). NVivo is very useful at this stage as it links the indexes and codes to the transcripts. The result of this stage is a matrix output which summarises the data, which is particularly useful when working with multidisciplinary teams (Gale et al., 2013). The charts for each theme and subthemes can be found in Appendices (Appendix 12, 13 & 14).

During this stage, some of the themes were also re-named to better reflect the content. I also decided to split the sub-theme 'emotions' into 2 separate sub-themes: 'awareness of emotions' which was coded in the 'what students need to know' theme, and 'knowing mechanics not emotions' in the 'difficulties in teaching' theme, as teachers were talking about emotions in two different contexts- as something that students struggled with, but needed to know, and not being aware of the emotional side of relationships as a challenge in teaching.

Subtheme 'parental attitudes' was split into 2 subthemes: positive and negative attitudes. 'Positive attitudes' references were moved into the 'how to overcome difficulties' theme and the 'negative parental attitudes' into the 'difficulties in teaching'. Positive parental attitude can be enhancing factor in the process of education, whilst negative attitudes are something that teachers find challenging.

When reviewing the sub-theme 'attitudes towards LGBT' I decided to split it into two sub-themes: 'homophobia', which was left in the 'difficulties and challenges in teaching' theme and 'positive attitudes towards LGBT' subtheme, which was placed in the 'what students need to know' theme as tolerance was something that some teachers stated as a thing they try to pass to their students.

After the process of refinement of the main index of the theme 'difficulties in teaching', decision was made to leave only general problems of delivering sex education in it. Another sub-theme was created- 'cognitive abilities' where all references regarding students' struggles with processing or remembering information were coded. Some more specific references within the theme, for example about the need of prioritising, were moved to the appropriate sub-themes. In addition, subtheme 'negative stuff' and 'changing population' were merged with the 'general difficulties' subtheme as there was only one reference in each of them. Furthermore, 'socially inappropriate behaviour' sub-theme was created to accommodate all comments about students' challenging behaviour and 'lack of interest and/or not relevant to the student' sub-theme was added to the 'difficulties/challenges in teaching' theme.

The sub-theme ‘need for knowledge’, which was originally placed under the ‘what students need to know’ theme, was moved to theme 2 ‘how to overcome difficulties’. The decision was made because pupils’ willingness to learn, their need for knowledge, was a factor that could enhance learning and help teachers overcome some issues.

The ‘safeguarding’ theme was added to the ‘what students need to know’ theme, as the topic of being safe was considered a top priority by many teachers and in their opinion, pupils needed to be aware of it. What is more, the sub-theme ‘sexuality as a natural need’ was merged with the ‘rights’ theme as many of the quotes were overlapping.

The subtheme called ‘good practice’ in the ‘how to overcome difficulties’ theme was split into several sub-themes, namely ‘tools and techniques, ‘adapting to individuals’, ‘role-plays’, ‘being positive’, ‘other tips and advice’. This was done, as the subtheme was very extensive. The sub-theme ‘skills not knowledge’ in the same theme was removed as the quotes in it were referring to one skill only- assertiveness. The quotes were incorporated into ‘making choices’ subtheme, within theme 3.

V. Mapping and interpretation.

In this stage, key characteristics of the data are pulled together, mapped and interpreted as whole. This includes defining concepts, finding associations, providing explanations etc (Ritchie & Spencer, 1994).

During the process, it was decided not to include the ‘need to be in a relationship’ and ‘other’ themes in the final analysis as they were not linked to the remaining themes and did not address the research questions. The ‘what students need to know’ theme, was rephrased to ‘important areas’. Overall, as guided by the framework analysis, the two main themes were challenges when teaching and ways of overcoming the difficulties. Teachers and educators talked about some general problems they do come across in their work, such as level of comprehension of their students, as well as more specific struggles such as using sign language to communicate with some people they work with. Some challenges were also associated with the specific aspects of the subject of sexual health education, for example, embarrassment of the students. At the same time, interviewees also shared their ways of dealing with difficulties they encounter. This included examples of good practice from their workplace and their experience, but also general things such as the need to repeat everything or using simple language. This potentially was done to give an impression that they were not “giving up” when facing challenges but were actively looking for ways of overcoming them.

Another important aspect of teachers and educators' work which was mentioned frequently was about the most important areas in their opinions, priorities of their work and what did they hope for their students to know when they finish their education/course, despite all the challenges encountered. As this links with the previously established framework, a decision was made to add it.

The final three themes are as follows:

1. Challenges and difficulties in teaching.
2. How to overcome difficulties.
3. Important areas

Each of the stages described above was discussed with the supervisory team. Themes and sub-themes with supporting quotes were sent regularly for review and the process of decision-making i.e. inclusion or formation of themes was challenged and debated.

5.3 Findings of the Framework Analysis

The following section will detail the analysis of each theme and its subthemes. The analysis will include excerpts that will illustrate examples of the themes and sub-themes.

5.3.1 Theme 1: The challenges and difficulties to teaching.

Theme 1 revolved around the challenges and difficulties to teaching about sex and relationships to people with LD. Teachers and educators talked about some general problems they come across in their work, such as the level of comprehension of their students, as well as more specific struggles such as needing to use sign language to communicate with some people they work with. Some challenges are also associated with the specific aspects of the subject of sexual health education, for example, the embarrassment of the students.

The following sub-themes were categorised under the theme:

- General challenges and difficulties to teaching
- Lack of interest and/or not relevant to the student
- Socially inappropriate behaviour
- Black and white thinking
- Awareness of background / past experiences
- Cognitive abilities

- Heterogeneous groups
- Homophobia
- Emotions
- Negative parental attitudes
- Prioritising
- Puberty and anxiety
- Difficult topics

General challenges and difficulties. Teachers and educators frequently emphasised how difficult and challenging their job could be. One of the problems is that teachers have to pass knowledge to students, whose understanding of the issues could be very different to theirs, for example due to lack of experience or their level of functioning.

Two of the participants commented that language could be a barrier- "I think language is a huge difficulty." (E3) Using words that are easily understood, but also giving the students the right terminology.

One of the teachers stated that sex education could be a problematic subject to some people as it was still considered by many people as a taboo topic: "it's naturally a bit of taboo topic really, particularly here in England. (…) I think for some people that's a real challenge." (T8)

Lack of interest. Three teachers struggled with the fact that some of their students were not interested in what was being taught. One of the teachers expressed the belief that "a lot of them because of their immaturity are thinking: 'this is never going to happen to me.' So they are almost shutting it down, the barriers are coming down. It's just not immediate enough for them if you see what I mean" (T7). He also stated that it could be down to the fact that they do not believe that the area of relationships and sex is relevant to or meant for them, at least not in the near future. Another teacher remarked that the lack of interest was due to the fact that for some pupils the topic of sexuality was very new. Nobody had ever discussed it with them, so they were learning about things they had not heard of before: "I suppose they ask less questions about things, because they're finding out about things they know very little about" (T3).

Socially inappropriate behaviour. Two interviewees mentioned students' inappropriate behaviour during the lessons, but also outside of the school as a challenge- "there is a lot of extremely sexualised behaviour" (T4). As individuals "operate on a very

sensory level" and "have no concept of public and private," incidents of masturbation or inappropriate touching of others happened at school and teachers had to deal with that. Some teachers might find it difficult to explain to somebody why they should not do something that makes them feel good and enjoy doing. That can be very challenging when working with individuals who have very little awareness of their bodies and what is socially acceptable. Teacher 4, who spoke about this issue, found it hard, as she felt that pupils' inappropriate behaviour could lead to somebody being in trouble "even arrested." She saw it as a dilemma between protecting her students, but also letting them "live this happy bubble." She concluded by saying "often, you have to be quite cruel to be kind about it" (T4). The situation could be even more difficult with students whose disabilities were not affecting their physical appearance: "especially with something like autism where it's hidden, they're not physically any different to anybody else" (T4).

One of the educators felt that socially inappropriate behaviour could be occurring because it requires the person to grasp many complex concepts, such as empathy or reciprocity, which are difficult to teach and comprehend:

> "That's being quite sophisticated process to put yourself in a position of the other person and ask the question whether they feel the same way about me (…) reciprocity is quite a complex concept. And so is the consensual stuff, which I think is quite difficult to teach. And empathy is another one that has been difficult" (E2).

The same educator also added that other concepts that were difficult to convey were boundaries and consent but ignorance of them could also lead to inappropriate behaviour. She stated that topics such as body parts were easier to teach, as they were more concrete and specific.

Black and white thinking. Four teachers said that one of the challenging aspects of delivering sex education to people with LD, especially those on autistic spectrum, was the black and white thinking of the students and lack of understanding of the subtle areas: "for most students on the autistic spectrum everything is white or black (…) there is no room for shades of grey" (T2).

This way of thinking could be particularly challenging when it comes to educating people about social norms and rules, as they tend to change depending on the circumstances. Hence, some teachers struggle with it and they try to overcome it by giving many real life examples:

> "It's those grey areas, why is it ok to do this in this situation, but not in this and actually sometimes you have to think about as many situations as you possibly can and say: 'if you did that here, do you think you would do that there; why wouldn't you do it here, you could do it there'" (T10).

The black and white thinking affects teaching styles. Teacher 8 commented that "the teaching style also has to be adjusted to make sure that they are no shades of grey and everything is made as clear as possible."

Awareness of background and past experiences. One of the biggest challenges when delivering sex education to students with LD was the possibility that they have been abused in the past. It is vital that teachers are cautious when discussing sensitive topics. Teacher 5 stated:

> "You've got to be aware of the background, things that may have happened to the student. You've got to sometimes be incredibly sensitive about it and be aware that some issues may not be comfortable with all the students so you have got to gauge it."

One of the teachers commented that she needed to be aware of student's experiences as "those young people, who have been abused in the past, sometimes they want to avoid any discussion about relationships and sexual relationships" (T10). Hence, without this knowledge she would not realise why pupils were not engaging or responding. Furthermore, she could adapt her lessons to address the negative issues by "saying to those young people: 'you're entitled to have a good relationship; that person did you harm, but you're growing up and you're entitled to have good experiences.'" She concluded by saying: "that's quite tricky, because I don't always know [about the abusive experiences]" (T10). The UK government guidelines specify that "the sharing of information between practitioners and organisations is essential for effective identification, assessment, risk management and service provision" (p. 13, DfE, 2018). It is important that these guidelines are translated into practice.

It is not just sexual abuse that the teachers should be aware of, but also other types of abuse, as well as complicated family relationship, addictions and illnesses. Teacher 3 expressed a belief that "if you're looking at things such as family relationships you need to know before you start what the family relationships are for the students within your class, because you can... people can, you know, get upset very quickly, you know, you have to be sensitive." Hence, people delivering sex education had more "than just the curriculum to deal with" (T3).

Cognitive abilities. Another big challenge when teaching people with LD is their level of understanding and cognitive functioning. Teacher 4 said: "on a practical level also, it's hard when you are working with people with such a low level of development and communication. Just to be able to get the message across." Some teachers found it difficult knowing how to pass on the knowledge, how to assess the level of understanding and "how you make it relevant, how do you safeguard them, how do you give them enough information when they not really make sense of the world around them. That's a challenge" (T6).

Several interviewees stated that they found it difficult to know whether participants understood what they were trying to teach: "sometimes it's quite hard to pick up whether they understood something or not" (E2). This issue is discussed in more details by Finlay, Rohleder, Taylor and Culfear (2015).

Heterogeneous group. The next factor that can make teaching and working with people with LD difficult was the different levels of functioning of students. Despite the fact that most schools try to group pupils according to their levels of cognitive abilities, some teachers still face a situation when "sometimes in a group you have some that are very sharp and know a lot and others in the same group that are not taking in" (T2). It is not easy to make teaching inclusive and to address things if "they are all very different levels, so it's very hard to get the group sorted out, because they all, sort of understand at different stages as well" (T1). It is especially challenging to include those students "who are functioning at very early stage, you know, almost childhood, and how you get those people included as well is very difficult" (T6).

Homophobia. Four of the participants mentioned that the level of homophobia among their students was high and learning about LGBT issues was "something that students aren't comfortable with" or sometimes even "people would just not have it" (T10). As stated by Teacher 7, this could be due to the fact that "some of them are very prudish." He gave an example of pupils' reactions during his lessons to a video clip featuring homosexual and transvestite behaviour:

> "In the prejudice and discrimination lessons that I've been doing at the moment, we put on Christina Aguilera video "Beautiful" and the sight of two boys kissing- one class -absolutely no problem. There was a few sniggers when there is a middle aged man, who puts a bra on and some of them went: "that's a bit strange" , but the boys kissing, "so what, great!" (…). But the next class, actually the more able one, the

people doing level 3, there were several students who turned away “I can’t look at it, that’s disgusting!”, so we do have all kinds of barriers to cross.” (T7)

Teacher 1 expressed an opinion that the negative attitudes towards the LGBT community were a results of black and white thinking typical for individuals with ASD: “for most students on the autistic spectrum everything is white or black. They have learnt that man and woman, mum and dad, two men-no.”

What is interesting is the fact that in this sample participants reported that the less able the students, the more positive attitudes towards LGBT they present. Two teachers working with students with more profound difficulties observed that “my students are very accepting of all of it” and “ours don't care.” Teacher 4, who worked mainly with autistic students, stated that they were very tolerant “because they walk around in this bubble of total tolerance, total acceptance, everything, and they don't have a concept of: ‘it's weird that I like stroking people's hair’ or somebody is falling on the floor, because they want to lick somebody's feet, they just do it.” She also observed that within the school she worked at, the numbers of homosexual, transvestite or transsexual behaviours of students were higher than in the general population. She believed that “it follows that you are going to have more open transvestites, gay, lesbian people with special needs, because they don't have that understanding that other people are going to judge them” (T4).

One of teachers believed that the reason why young people might find the topic of different sexualities challenging was the fact that they were confounded about their own sexual orientation-“that’s also [homosexuality] something that students aren’t comfortable with, but there’s quite a lot of students with very confused… quite confused sexuality” (T8).

Emotions. Two of the teachers commented that their students might have some theoretical knowledge regarding for example sexual intercourse, but they do not seem to know much about the emotional side of relationships- “you also get pupils, who think they know it all, but actually they know the factual side of things and not the relationships” (T3). This could be because teaching practical, concrete things was much easier than trying to explain the emotional side of things, especially to students who struggle with recognising their own and others’ feelings. The topic of emotions could also be difficult to understand for some pupils, in particular those on the autistic spectrum. In addition, any type of relationships, especially romantic ones, involves a wide range of emotions, which can be problematic to explain and comprehend.

Teacher 7 expressed a belief that without understanding of their emotions, students could not apply the theoretical knowledge:

"So I am always conscious about SRE that it's not just about… they need to know the mechanics, they need to know the different forms of contraception etc., but they also need that emotional understanding of themselves if they are going to really use that knowledge."

Negative parental attitudes. The attitudes of parents towards their children taking part in sex education are varied and many teachers find those parents who do not support it, difficult to liaise with. Teacher 4 saw discussions with parents about for example the inappropriate, sexualised behaviour of their children, as the most challenging aspect of her work.

> "I think if there was anything [that I find difficult], that would be discussing with a parent, who finds it very embarrassing and you having to explain to parents some of the things that their child is doing and they can either deny it or say: 'what are you going to do to stop it'– that's when it gets hard, because, you know, you're dealing with that and there's often within our school a lot of cultural differences 'oh, my child doesn't do that, girls don't do that' and you're like: 'yes, she does, very often' ...err... so those kind of things are hard."

The situation when some mothers and fathers expect the teachers to eliminate the inappropriate, sexualised behaviour of their children can be difficult. Furthermore, many parents do not accept the fact that their children are sexual beings. Educator 2 recalled an example of parents, who did not want their daughter to take part in sex education so she was not aware of having sexual organs.

> "I came across parents who have said: 'I don't want her to know that she has got a vagina, I don't want her to know that she can put anything there in case other people would start putting things up there.'"

***Prioritising*.** Five of the participants commented that one of the challenges they had to face was the fact that there were many areas they wanted to cover in their lessons or workshops, but quite often, they did not have enough time. Educator 5 said: "there is so much that we would love to talk about but we have slotted times." Because of the limited time, they needed to decide which topics were the most important or relevant to their students and "just trying to slot those really important things in" (E5).

Puberty and anxiety. A further challenge, particularly for people working with youngsters on the autistic spectrum, was their difficulty with coping with the changes linked with puberty. Body changes during adolescence could cause a lot of anxiety, so teachers had to make sure that they talk about it in advance to prepare the students for the onset of it. One of the teachers stated that "we'll always teach about puberty and how your body changes, because obviously our kids have difficulty coping with change and so when their body starts changing, obviously that's something that they totally cannot control, that can be frightening for them. So we do a lot of work to prepare them for that kind of thing" (T4).

Difficult topics. Apart from anxieties associated with puberty and growing up, there were other topics that some students find difficult to learn about when they take part in sex education sessions. One of them was the area of sexual intercourse. Educator 2 said: "most of them are actually horrified about, sort of, sexual intercourse." According to this educator, the main reason why participants of the sex education workshops are "terrified" of the topic of sexual intercourse was the fact that they did not have understanding of what it meant and involved.

Some pupils with autism found talking and hearing about close relationships difficult- "some of them are on the autistic spectrum, so they are blocked, they don't want to know about this or they do want to know about it, but they think it's dirty or whatever" (T1). Again, the aversion can be so deep, that students did not want to hear about it.

For some people with LD having a closer look or needing to touch a contraceptive or model of a penis was be a bridge too far and some students may find it very discomfiting- "it's usually the contraception or when we get the condoms out, some of the boys get very embarrassed" (T10).

5.3.2 Theme 2: How to overcome the difficulties.

Theme 2 consist of examples of things that the interviewees in this sample considered useful in their practice and tactics from their work that they found helpful. Interviewees shared their ways of dealing with the difficulties they encounter. This includes examples of good practice from their work place and their experience, but also general things such as the need to repeat everything or using simple language. It includes of the following sub-themes:

- Tools and techniques
- Adapting to individual

- Role-plays
- Sense of humour
- Self-esteem
- Working with parents
- Repetition
- Starting early
- Need for knowledge
- Other tips and advice.

Tools and techniques. This subtheme includes examples from the participants' work, strategies they have developed to make their work easier or methods and resources they use. Most strategies used by teachers in this sample can be applied to teaching all subjects, and are not specific to the SRE only.

Educator 2 said: "I think one of the important things in teaching people with disabilities is that you need a variety of tools." This was important because "different things work with different students at different times" (E2). As mentioned earlier, people with LD are very heterogeneous group. The greater the diversity of materials used, the greater the chance of getting the message across to a large number of pupils. Also students' needs change. In addition, there are many different topics covered in sex education and whereas students can benefit from, for example, role play to understand one topic, another tool, like social stories, might be useful to learn something else.

In the opinion of Teacher 9, trying different things was a good way of making sure that pupils understood what was being taught to them- "for our students, you may say one thing and they'll look at you: 'what on earth are you talking about,' but actually when you go around in three different ways, they get it, then they understand it. Then they will come back and say: 'yes I know, I understand it' so it's about being flexible and diversifying stuff."

Using "a lot of visual work," concrete aids and resources appear to be a strategy used by many teachers in this sample to help their students comprehend and remember the material better. Teacher 1 said that because "you learn a lot by seeing (….) with all the resources visual ones are the most beneficial."

Teacher 4 stated that it was very important to not only use a variety of tools, but a range of methods of communication as well. It helps to be as inclusive as possible. In the school where she worked "we tend to use a combination, (…) either symbols, sign language

or we use gesture with them (…) but everything's made very visual and objects references also. Everything has to be extremely visual rather than verbal."

Adapting to individuals. In order to meet the needs of the students, education needs to "remain very flexible and responsive to what they need" (T2). Teacher 1 said: "I try very hard to adjust what we do to particular pupils and quite often we don't follow a set programme every year." At times, the topic of the lesson could be dictated by a difficulty or issue that students face at particular time. Teacher 10 stated that "when there is an issue or there is something worrying them or something has come up, then we, I can change the lesson." Many interviewees appreciated the opportunity to be flexible in their work and the ability to adjust the programme depending on the needs of the students.

Teacher 8 expressed the opinion that despite the fact that he sometimes changed the topic of the lesson in response to particular issue, like "bullying done on the yard at lunch time," it was important that the education was not only "reactionary and just respond to whatever happens." According to him, "you can go down wrong routes if you do that, because you don't end up with very broad view of what PSHE is or how it should be" (T8).

According to Teacher 8, another reason why the education should be adapted to the needs and interests of the students was that it meant that the pupils were more motivated to learn about it. In his opinion, teaching things that students found interesting meant that they did not necessarily learn quicker, but were more driven and inspired: "I wouldn't say they find it easy, because they generally find learning challenging, but they always learn about something if they're motivated, which is the same for everyone" (T8). Participants with LD in the study by Löfgren-Mårtenson (2012) reported that there was a relationship between finding things interesting and remembering them better.

In order to establish the needs and interests of the students, they need to be given the opportunity to ask questions. This could be done by reminding pupils that they could approach the educator at the end of the sessions or by students writing down any questions they had but were too embarrassed to ask them during the lesson.

Role-plays. Helpful tools, used by many teachers in the sample were role-plays and scenarios- "we do lots of role-play around difficult situations, what could they say [in various situations]" (E3). Role-plays were useful and beneficial for many reasons, for example, they could be used for practising or preparing for specific situations. Such an approach could be

also very beneficial, “because we would talk about things in scenarios as well and trying to get them to understand other people's points of view.” (T3)

Sense of humour. According to some participants in the sample, a sense of humour could be used as a way of dealing with embarrassment. Educator 5 stated that she found a sense of humour very useful and “approach it [session] in a fun way to make them [pupils] relax so they can feel open.” This participant would start her SRE workshops in an entertaining way: “I think these ice breakers are really, really important. Make it fun” (E5). In her opinion, such an introduction to the potentially difficult topic, meant that students felt more comfortable and became more open. Teacher 9 also practised an ice-breaking exercise at the beginning of her teaching, not only to make the students feel more relaxed, but also to make them aware that it was “ok to talk about these things.”

A sense of humour and laughter could be useful in not only making students feel more comfortable, but also in building trust and a good relationship with educators. Teacher 3 expressed an opinion: “I think that having a good sense of humour and that sort of thing is really, really important.” However, Teacher 8 presented a different view. In this interviewees’ opinion, it was best not to get involved in the “silliness” and his way of dealing with students’ laughter, which could be a reaction to embarrassment, was not to react and “just sort of press on through.”

Educator 5, who expressed the belief that each session should start with a fun activity also commented that it should end in a positive way- “we finish on a really high note.” In her opinion, because the topics covered in the SRE education could be difficult and “some parts we are talking about are not so high, especially about safeguarding. So we always end up [on high note].” Teacher 7 also mentioned practicing short breaks when discussing challenging subjects, during which he would emphasise to students that despite many risks in life, positive aspects outweigh them.

Self-esteem. Two participants saw increasing student’s self-esteem as a task that schools should be addressing. Having higher levels of self-worth could positively affect the way pupils learn, but also potentially reduce some risky behaviour. Teacher 7 mentioned that in his opinion, because some students, especially girls, had unfulfilled needs and low self-image, they were “throwing themselves at boys.” Hence, work on improving students’ confidence should be included in teaching programmes.

In the Levenson-Gingiss and Hamilton's study (1989), SRE teachers working in mainstream schools expressed a belief that it was important to teach students methods to enhance self-esteem and interactional skills. To incorporate issues of self-esteem, personal autonomy, and skills in SRE was also recommended by Sieg (2003).

Working with parents. Working closely with parents was an important factor, mentioned by many participants, in overcoming some of the challenges of delivering sex education to people with LD. Cooperation between parents and school was crucial to improve challenging behaviour, for example masturbation in public. It was important to ensure consistency and reinforce the message of what was acceptable, when and where. Routine was especially important when working with students on the autistic spectrum. Teacher 4 summarised it in the following way and gave a supporting example:

> "With something like autism it's so routine led, that if we're doing it at school and it's being done at home as well, it's much more likely to work than if they're being given mixed messages. (…) And so we have to be working with parents in that way, it's really important."

Working closely with parents seems to be especially important in the situation when carers might have ambivalent or negative attitudes towards their children taking part in SRE's lessons. Teacher 6 said that "we always try to invite parents to look at the resources and talk about what is going on if they are not sure or uncomfortable." Seeing the materials and topics covered could persuade parents of the need to give permission for their children to take part in the education. Parents' anxiety and uncertainty about the SRE lessons or workshops could be reduced by giving them information beforehand about it. Educator 4 pointed out that it was "not a permission seeking thing, it's just about keeping people informed and for them [parents] not to worry about."

Many teachers indicated that in their schools, letters to parents were sent out "at the start of every semester to say what we are going to teach" (T7). Teacher 8 stated that by doing that and "explaining the topics that will be covered" parents had the opportunity to object and potentially withdraw their children from SRE lessons. Despite the fact that all schools practised giving the parents an option to remove their children from sex education, according to the teachers in this sample, it rarely happened.

Craft, Stewart, Mallett, Martin and Tomlinson (1996) in their article emphasised that if there was trust between parents and schools, carers were less likely to exercise the right to

withdraw their children from SRE. However, parents of children with LD in the UK interviewed by Garbutt (2008) were not happy with the level of information they received from schools about the content of SRE taught to their children and complained that the schools did not discuss the topics covered with them first. Interviewees in this study also commented that many parties, such as parents, nurses and teachers, should deliver the knowledge and they emphasised the need for a partnership working (Garbutt, 2008).

Repetition. Another method for overcoming difficulties when teaching, especially issues with understanding and remembering information, mentioned by interviewees was repetition- "we have to re-visit things a lot" (T3). Repeating things often helps students grasp the topic better and retain it for longer. This means that "quite often you have to go back, repeat it and repeat it, because they don't understand it fully the first time" (T9).

Such an approach to teaching means that it could be challenging to cover all subjects as teachers spent a lot of time "visiting it again and again" (T10). However, this method seems to be effective as "the more you go over it, the more it does eventually, some of it stays" (T2).

Starting early. Sex and relationships education should start as early as possible in order to make sure that it is effective and that the students have the tools and knowledge to protect themselves, according to three participants in the study. The Head teacher of one of the special schools that I visited stated that in his opinion it should start as early as nursery (D. Stewart, personal communication, July 10, 2015). According to him, young children should start by learning about body parts and making choices. Teacher 1 reported that in the school where he worked, sex education started in the primary school: "just learning about their bodies, public- private, stranger-danger, this sort of thing." As stated by this teacher, starting education early was especially important for children with LD, as they were at greater risk of being abused.

In the study by Garbutt (2008), "several" parents of people with LD expressed opinions that sexual education should start early. The age of 9 or 10 was suggested as the right time to give youngsters information about sexual health (Garbutt, 2008). In Wilkenfield and Ballan's study (2011) educators varied in their views regarding the best time to start sex education, but all agreed that it needed to be done before the onset of puberty. However, in Löfgren-Mårtenson's study (2012) conducted in Sweden, several young people with LD said

that they received information about sexual health when they were too young, which some of them found embarrassing and frightening.

Need for knowledge. An additional factor, that could enhance the learning and overcome potential difficulties was the fact that "most of our students are open, they want to learn" (T2) and "they just really want to know" (T1). According to participants in this sample, the majority of people with LD were interested in the topic of sexual health and relationships and wished to have more information about it.

Other tips and advice. Another issue mentioned by some of the interviewees was boundaries regarding personal life. Educator 4 expressed an opinion that teachers should not share their private life with students and use, for example, illustrations from their life. She found it challenging "to keep boundaries and not talk about my own experiences, because it can help, but it can also come back to bite you too, so I guess keeping boundaries [is the most difficult]." Teacher 9 voiced a different opinion. In her work, she was "pretty open about my family and my own experiences and that sort of puts me on the level with them rather than me standing in front of the classroom and saying: 'right, this is what we do.' I like to give them real life examples." The matter of being open about personal experiences and keeping boundaries seems to be very individual and depend on the personal decision of each teacher.

Teacher 5 expressed an opinion that feeling comfortable about the topics discussed could potentially influence the effectiveness of the teaching. He said that: "you try really hard not to feel uncomfortable yourself when talking about these things, which is sometimes quite hard, but I think they can pick up the fact that you aren't comfortable talking about it." Another participant emphasised that it was important that not only the leading teacher should feel at ease, but supporting staff as well. Teacher 9 stated that she "always said to the staff who supports students: 'if you feel uncomfortable, please feel free to say: "I'm sorry," and go out of the classroom for a while." The need to feel comfortable when teaching sensitive topics was confirmed in the study by Hamilton and Levenson- Gingiss (1993), who found that teachers who felt more comfortable were assessed more positively by their students.

Another thing that some participants in the sample found helpful was doing research together with students about resources in the local area "where they could go to get that information, who could help them on a range of topic" (T9). Teacher 10 also discussed with her students "websites and places you can go locally and they can find where their local clinics are. It's not just about sex, but all sort of things." She would also visit Sexual Health

Clinics with her students, not only to make them aware of places where they could receive advice or treatment, but also to make them feel more confident about visiting venues like this. The same interviewee said that she would spent time trying to explain to her students where to find "proper advice; advice that's reliable."

Adolescents with LD in the study by Löfgren-Mårtenson (2012) mentioned many of the above techniques. Participants stated that they found useful: learning in different ways, by a variety of tools, having information repeated, gender divided smaller groups, writing questions in advance and putting them in an anonymous box, teacher having a sense of humour. However, the usefulness of role-plays was declared by a few only.

5.3.3 Theme 3: Important areas.

This theme summarises what the participants considered priorities in their work, subjects regarded to be the most important ones for their students to be aware of. The following sub-themes are included in it:

- Safeguarding
- Internet safety
- Knowing what is right and wrong
- Making choices
- Human rights
- Positive attitudes towards LGBT
- Developing social life and skills.

Safeguarding. Safeguarding was seen as a "paramount," "probably the most important thing" and "the first priority" of most of the teachers in this sample (9 participants). It was vital, "because whatever the level of their learning difficulty or disability, people are very vulnerable" (T3). In the opinion of Teacher 7, the topic of "how to stay safe" was so important that "it virtually covers the whole of SRE."

Another factor having an impact on the increased vulnerability of people with LD was the fact that individuals might not have the confidence to report abuse. Sometimes people with LD might not be aware, whom should they inform if something worrying was happening. That is why Educator 2 stated:

> "I think that is critical that every person with learning disability has a safe person to whom they can talk intimately about anything that might be worrying. Sometimes it's

a parent and sometimes it's another family member, but I always encourage parents to identify to their child and to have agreement about who that safe person will be."

Many teachers considered educating their students about the right to protest if they were not happy with what was going on, as a key to improving safety- "it is all about giving them a knowledge about if somebody is taking advantage or behaving inappropriately towards them, they have a right to say 'no'" (T6).

In the study by Swango- Wilson (2011), individuals with LD expressed the wish to know more about ways of reporting abuse from care givers, as topic that should be included in sex education.

Internet safety. The topic of internet safety seems to be important in the eyes of some of the teachers, mainly "because our students very rarely go out, most of them…a lot of them do sit on Facebook, play video games with live links" (T1). Due to limited opportunities for socialising, for some of the students, being on-line was a prime way of spending their free time and entertainment. Sometimes, the internet was the only place, apart from school, where pupils with disabilities could meet new people- "it's their only chance of interacting with others" (T10). This could be potentially dangerous and "we did have situations where somebody wants to meet up with somebody, so we really went into that" (T1). In the study by Löfgren-Mårtenson (2012), adolescents with LD expressed an opinion that the topic of internet safety was relevant and important to them and it should be discussed in SRE.

Teacher 8 called attention to the fact that for some people with LD, the media and internet were their main source of information, which could lead to incorrect knowledge and "distorted views," especially if individuals had no capacity to assess the accuracy of what was seen by them. This is in line with findings of Löfgren-Mårtenson (2012), who reported that adolescents with LD were more likely to be affected by unrealistic images of men and women, especially those presented in pornographic materials.

Knowing what is right and wrong. According to some of the participants in the sample, one of the most important things that students should be aware of at the end of their education was what was right and wrong, appropriate and inappropriate behaviour. This is illustrated well by a quote from Teacher 1, who said "it's important to channel their education so they know exactly (…) what is ok, what is not ok, what is acceptable, not acceptable." Such a knowledge was crucial so "they don't get themselves into trouble, they don't get somebody else into trouble, and they don't become victims of crime" (T1). The topic was

important as many students had “a problem of not recognising the boundaries” and “lack of social inhibition” (E2). Therefore, many teachers chose to “teach about boundaries, rights, legal things. I think consent it's a huge issue” (T8).

Teacher 4 commented that the discussion about the law and appropriate behaviour, was often initiated by her students, who “want to know that what they’re doing it's ok. They want to know that they're not wrong or that they're not going to get in trouble and they don't need to worry about things and they like to be prepared for what might happen.” That meant that teachers “have to be very aware of things such as what are the laws regarding, you know, if you can order a porn on the internet, which a lot of our kids would do, and actually there are very specific laws about what is ok and what's not ok. And I think that's a real short falling for a lot of teachers particularly” (T4).

Making choices. An ability to make choices was considered by many participants in the sample as one of the priorities of their work with students with LD. Being able to “help to empower them really to be able to make their own decisions about what they do in their life” (E3), was mentioned by eight interviewees as a key element they hoped to achieve during the course of education. The task was not easy, “because they don't like choice” (T4) and “some of them cannot make a choice” (T10). Unfortunately, “often with people with learning disabilities, decisions are made for them” (E3). This was because “either somebody thinking that they know best or it’s quicker, easier and life goes on in that way.” According to Educator 3, it was the role of teachers to give students’ the information and confidence to say: “actually I would like to do this” or “I do not want to do that’” (E3).

Being able to say “no” was also important to decrease the vulnerability of people with LD. According to Teacher 10, it was crucial that “they know what they want and not be swayed by other peers or other people, because that's when their vulnerability comes in.” The interviewee further stated that individuals “shouldn’t just go away with something that somebody says, they should go and decide themselves” and that it was her “main target” to make her students “say ‘yes’ and mean it or to say ‘no and mean it.”

Human rights. Interviewees spoke about the rights of the people they worked within two contexts: the right to the knowledge and the right to be in a relationship. The majority of participants in this sample (11) emphasised that individuals with LD had the same rights as people without impairments, and it was their role to make students aware of their entitlements and that sexuality was a natural need. Pupils needed to know that they “have a right to

knowledge and a right to make decisions around their sexual lives…they are sexual beings" (E1).

Teacher 8 expressed a belief that individuals with impairments might not be aware of their rights or be able to practice them, due to the attitudes of people working with them: "it's decided by the people who work with them" (T8).

Teacher 6 commented that another reason why it was important that "as the pupils grow up they have awareness of, you know, sex education, contraception, again keeping themselves safe" was "also making sure that because they have got special needs they are not discriminated against it." Being aware of their rights could help people to practise them, regardless of the views of others, "because they're members of society, those who want to, should be able to have partners, as it was healthy for them to have relationships" (T6).

In Wilkenfield and Ballan's study (2011) on the views of educators towards sexuality of individuals with LD, the topic of sexual expressions as a basic human right was the main theme reported by the interviewees.

Positive attitudes towards LGBT. As mentioned previously, according to the participants in the sample, attitudes towards LGBT behaviours varied a lot among the students. Many students, especially those with mild impairments, presented negative attitudes as reported by the teachers in this sample, as well as in other research (Konstantareas & Lunsky, 1997; Löfgren-Mårtenson, 2009). At the same time, according to Teacher 4, a number of pupils, particularly those on the autistic spectrum and with more severe disabilities, had positive attitudes "because they walk around in this bubble of total tolerance, total acceptance." Several teachers reported that "there are students here that would be in same sex relationships" (T1). Therefore, it was important to teach about different sexualities in the sex education at special schools.

People with LD needed the reassurance that if they were attracted to people of the same sex, their feelings are normal, especially because sometimes they come from families who present a very negative attitudes towards the LGBT community. According to Teacher 2, it was important that "we teach them that as human beings this is acceptable in the society. We don't pick people out. It's ok to have same sex relationships and they exist (…). Everyone has got a right to a relationship whether it's the same sex or not."

Developing social life and skills. Another important competence that students should possess, according to some participants, were social skills. Teachers and parents should support pupils to attend activities outside of the school to practise them. If this was not done, it could lead to loneliness and social isolation: "when they leave school, they go to college and then everything stops. If they are not going to get into a workplace or whatever, so they then become very socially isolated" (T3). Therefore, "helping them to have a social life and not be lonely" was an important thing. However, that was not an easy task as most of the social events organised by school were supervised by staff and therefore were a "quite controlled environment" and people were just socialising with their "best friend from school, who is probably not somebody they're going to be in a relationship with" (T4). Another difficulty with being supervised was that staff presented potentially negative attitudes towards certain behaviour, for example kissing between pupils, but also did not want to be seen as responsible, if, for example, sexual intercourse between students happened, whilst they were on duty.

The lack of social skills, opportunities for socialising and "staying at home and watching television all the time and never venture out" could lead to a situation where "they [people with LD] have little knowledge of people" (E5). The fact that some individuals with disabilities were "insulated from the real world" could also mean that they "are likely to stay in that teenage frame of mind much longer, in that sort of bigoted, tunnel vison for a lot longer than possibly other kids who are going out" (T10). Overall, many teachers in the sample saw the development of students' social skills and creating opportunities for socialising as a very important aspect of their work.

5.4 Résumé of the Answers

An overview of the responses to the interview questions is presented below. Answers to the main questions asked during the interviews (not including those aimed at building rapport, prompt questions or additional queries that were asked in response to what was said) were summarised and quantified.

Do you think providing sex education is important?

All interviewees agreed that the sex education was very important. According to the participants in the sample, the main reason why it was essential was to help students stay safe (9 participants).

When you give sex education sessions, what are some of the typical things you would talk about?

The most common answer (10) was that it varied and that the teaching was tailored to the needs and wishes of the individuals participating in their lessons or workshops. The other frequently mentioned topic was safeguarding and how to stay safe (5).

What do you find most difficult or uncomfortable to talk about?

Eleven interviewees stated that there was nothing that they felt embarrassed about or struggled to teach. One teacher reported that she found the topic of masturbation and "penetration of the penis" difficult, as she did not know how to present it to the students. Educator 1 said that the most challenging situation she had to face was when participants at her workshops "realised they were being abused." Another educator (4) expressed an opinion that flirting was a difficult topic to explain to students, as it was an obscure one. Finally, Teacher 8 stated that he felt uncomfortable when needing to talk about disabilities to his students. He described it as an "elephant in the room."

Are there any things that you feel it is best not to talk about?

Most participants (10) stated that there was nothing they considered inappropriate or unnecessary to bring up with the students. Two interviewees said they would not discuss pornography. In the research by Löfgren-Mårtenson (2012) all young people with LD who took part in it agreed that pornography was not an urgent issue which needed discussing during SRE. One person considered talking about different sex positions as something that should not be mentioned to the students. One educator, who worked mainly with older individuals, did not see the need to discuss internet safety, as most of the people she worked with were not using computers. Another educator stated that she would not talk about or demonstrate sex toys to the participants of her workshops. Lastly, Educator 4 expressed an opinion that she would not disclose things about her personal life to the students and would not mention things "that would never happen to them."

What are some of the difficulties or challenges around talking about sex?

The aim of this question was to establish general difficulties and challenges around talking about sex. However, it seemed to be understood by participants in many different ways. Therefore, interviewees talked about a wide range of things when asked this question, varying from inappropriate room settings to sexuality being a taboo subject.

How do participants react to/behave when taking part in your workshops/lessons?

All participants reported that the students appeared to be embarrassed at the beginning of the lesson/workshop but felt more comfortable as the lesson progressed. This is similar to the findings of Schaafsma, Kok, Stoffelen and Curfs (2017) and Levenson-Gingiss and Hamilton (1989).

Which areas do participants have the best knowledge of?

Most interviewees (9) stated that the levels of knowledge varied a lot amongst individuals with LD. Three participants reported that the students had a good knowledge of body parts. Another three people said that they found that the students held good information about friendships, keeping safe, condoms and staying healthy.

Which areas do they have the least knowledge of?

Four participants stated that the least known areas depended on the individuals. The rest reported that the students had the least knowledge about:

- Social awareness
- How to become pregnant
- Mechanics of sex and emotions
- Consent
- Contraception
- Relationships
- Body parts
- STI's
- Contraception, sex, rights and social skills
- Sexual intercourse
- Tolerance

What factors affect their levels of knowledge?

Seven of the participants in the sample stated that the factor that had the biggest impact on students' level of knowledge was their cognitive ability, capacity to learn and disability. Other factors mentioned were: access to the internet, parental involvement, quality of education at school, people working with individuals with LD discussing the topic, opportunities to learn, self-esteem, and the family environment.

What do you think they need to know? What are the most important areas in your opinion?

The topic of safeguarding was the most frequently mentioned by the participants and described by many of them as "paramount" the "most important thing" they do (9 participants). This subject entails elements of protection. However, it would appear that in order to balance the impression that some students may have after hearing about the potential risks and dangers, many teachers were concentrating on making the pupils aware of their rights, especially when it comes to the right to be in a relationship or to have sexual contact.

What do they want to know about?

Three participants said that their students were not interested in the topic of SRE and hence appeared to have no questions. A further three interviewees stated that it varied what pupils wanted to know. Few participants (3) reported that students were "curious" and "intrigued" about "all sort of things." Other topics mentioned by the interviewees were: how to get a girlfriend/boyfriend, how to have sex, contraception and the law/people's rights.

What do they not want to know about?

The majority of the participants (11) stated that there was nothing that students did not want to hear about. Four interviewees reported that pupils were not keen to discuss the topic of homosexuality.

What hopes/needs do they have when it comes to relationships?

The most common answer (10) to this question was that the students hoped to be in a loving relationship and had "the same hopes and needs as everyone else."

What experiences do they have?

Most participants (11) expressed a belief that students' experiences varied significantly: from those who had no sexual experiences to ones that had had multiple

occurrences of different types of sexual activities. Three participants believed that the sexual experiences of their students were "limited." One teacher stated that pupils would not talk to him about their experiences and therefore he had no means of knowing whether they were sexually active or not.

How do parents generally feel about their children taking part in sex education sessions?

According to the participants (9) in this sample, most parents were happy for their children to take part in sex education and relieved that they did not have to do it themselves. Occurrences of carers withdrawing their children from SRE lessons were rare. However, as noted by the participants (3), some people felt anxious about the potential negative consequences of their children being taught about sexual health. Three participants noted that parental attitudes towards their children taking part in sex education were varied: "parental attitude is very mixed, so it goes from one extreme to the other" (T6).

5.5 Main Findings and Discussion

Most of the challenges reported by the participants in the study revolved around the abilities of the students, difficulties of the topic or parental attitudes. In contrast to previous studies (e.g. Rohleder, 2010; Wilkenfeld & Ballan, 2011) none of the difficulties associated with delivering SRE mentioned by the participants in this sample, were regarding their own attitudes or feelings, for example anxiety or apprehension about the topic or causing harm to the students. The only context when the participants would mention being worried was the vulnerability of their students. This could be due to the fact that the attitudes of the society towards the sexuality of people with LD appear to be becoming more positive. However, as suggested by Rohleder (2010), by discussing and concentrating on struggles in a generalised way, participants might be trying to distance themselves from their own negative views. This might reflect their emotional ambivalence about providing sex education to people with LD.

Another difference, compared to previous research (Howard-Barr et al., 2005; May & Kundert, 1996; Wright, 2011), is that none of the participants in this study mentioned inadequate training or professional preparation. No questions regarding training or professional preparation were asked during the interviews. Therefore, it is not possible to ascertain whether no reports regarding inadequate preparation were the result of feeling competent due to the training undertaken.

An additional challenge reported by participants in previous studies, for example in a study by Lafferty et al. (2012) conducted amongst different professionals and family carers working with people with LD in Northern Ireland, was the lack of resources. This was not an issue mentioned by the teachers in this sample. The reason for such a finding could be that in the past few years, many good resources, and tools for people with LD have been created and are widely available e.g. a series of books "Talking together about…" published by the Family Planning Association (Kerr-Edwards & Scott, 2003). Teacher 5 confirmed this in his interview. He stated that when he first started working in the field, it was a "hit and miss." However, in his opinion, over the past few years, things had changed for the better when it came to SRE: people were having more positive attitudes towards it, the resources were better and there was a wider choice of them and there were many more people working in the field who could advise or guide if need be.

Another barrier to efficient SRE reported by staff in previous studies (e.g. de Reus, et al., 2015; Lafferty et al. 2012) was cultural prohibitions stemming from religious beliefs. Such a difficulty was not mentioned by the interviewees in this sample, despite the fact that two participants worked in a Catholic school and one of the prompt questions was regarding the impact of religion on the knowledge of students.

An issue frequently mentioned by the participants in this study, was the fact that the students with LD were a heterogeneous group and presented various levels of knowledge. This was also reported by the educators in the study by Finlay et al. (2015). Working with individuals with varying and diverse abilities could be difficult, as lessons had to be adapted to the individual needs of the pupils, which could be challenging and time consuming, especially if they were many pupils in the group. Another implication of this was that a variety of resources and methods should be used. This was another key finding of the study. The diversity of the tools and methods used was also helpful to respond to different learning styles and make things more interesting, involving, and memorable. Practical implications of the study are discussed in more details in Chapter 5.6.

One of the most frequently mentioned and seen as the most important topic by many interviewees in this sample, was the vulnerability of the people with LD they worked with and the issues of safeguarding. Most teachers reported that their students lacked knowledge on how to stay safe. Some pupils, despite declared understanding of the issues of safety (e.g. not letting others touch them), did not possess skills, such as assertiveness, to implement that

knowledge, or due to unfulfilled, emotional needs, chose to act in contrast with the information they had learnt, for example stay in an abusive relationship. Such a state of things affected the teachers and made them see the issues of vulnerability and safeguarding in many different ways: as a motivation to work, but also a disincentive or reason to be frustrated. One teacher (7) mentioned that he felt that no matter how hard he tried, his students would still be prone to abuse. Cambridge (2003) made a similar observation that despite the fact that many individuals with LD appeared to understand the issues surrounding safer sex, it was frequently reported that safer sex was not practised by them in real life sexual encounters. Yacoub and Hall (2008) also found in their research that sexual knowledge of people with LD did not lead to safe sexual practices.

The topic of safeguarding entails elements of protection. However, it would seem that in order to balance the impression that some students may have after hearing about the potential risks and dangers, many teachers in this sample were concentrating on making the pupils aware of their rights, especially about the right to be in a relationship or to have a sexual contact. Such an approach is recommended by Garbutt (2008), Rohleder (2010) and Wood (2004), who stated that educators should take care not to demonise the topic of sex, but find a balance between safety and the fact that sex is natural and pleasurable and that people have a right to have a sexual life.

To summarise, findings of this study, which are new or different to previous research are: no reports of inadequate professional preparation or lack of training, no mention of own negative or ambivalent attitudes or anxieties regarding sex education of people with LD and absence of concerns regarding availability of resources. In addition, the lack of interest of students and recommendation to be aware of their background, were not mentioned in previous literature to my knowledge. Ways of overcoming difficulties encountered by the teachers and educators in their work (Theme 2) are discussed in the next section.

5.6 Practical Implications

One of the practical implications emerging from the interviews is connected with negative parental attitudes. Many teachers emphasised that the adverse or ambivalent attitudes of carers were something that they struggled with and could be a factor having negative impact on the levels of knowledge or attitudes of people with LD, which was also reported in previous studies (Cuskelly & Bryde, 2004; Hosseinkhanzadeh, Taher, & Esapoor, 2012). The solution to this problem suggested by several interviewees was close cooperation

between schools and parents, keeping carers informed about the content of the lessons, inviting them to have a look at the resources used and making sure that parents reinforced messages given by teachers regarding, for example, the problematic behaviour of the students. Craft et al. (1996) suggested having monitoring groups consisting of parents at schools, who could comment on resources, suggest important topics and offer peer support to alleviate anxieties and give advice. Some authors recommended that close collaboration should be present not just between schools and parents, but also include other professionals and the wider community (Blanchett & Wolfe, 2002).

Another piece of advice offered by the participants of this study was to use a variety of tools and methods and to be adaptive and flexible in what is being taught to the students. This is in line with recommendations from previous research (Löfgren-Mårtenson, 2012; Wood, 2004) and reviews of most efficient approaches (Schaafsma, Kok, Stoffelen, & Curfs, 2015), which suggest that using methods such as modelling or role-play improve the skills of individuals with LD. However, emphasis should be placed on skills rather than theoretical knowledge, for example, knowing how to use a condom was more important than being able to name all the methods of contraception, according to teachers in the sample as well as in findings from previous research (Schaafsma et al., 2017). In addition, when employing role-plays it was important to use various situations and contexts to increase the likelihood of generalisation (Blanchett & Wolfe, 2002).

It was also recommended to start sexual health education early. Topics taught at nursery levels could be regarding friendship, body parts, safety, diversity and, most importantly, making choices and being able to say "no." Such recommendations can be found in previous studies. In the study by Garbutt (2008), parents of people with LD expressed opinions that sexual education should start early and in Wilkenfield and Ballan's study (2011), all educators agreed that it needed to be done before the onset of puberty. In addition, education should be pro-active, rather than responsive to a problem (Garbutt, 2008).

Another practical implication emerging from this study was to include in SRE activities aimed at improving peoples' self-esteem. Several teachers saw increasing student's self-esteem as a task that schools should be addressing. Having higher levels of self-worth could positively affect the way pupils learn, but also potentially reduce risky behaviour. Improving self-image is also recommended by Cambridge (2003). It can be achieved by incorporating exercises aimed at increasing self-worth, for example asking students to say

something nice about each other or by showing pupils during reviews the progress they have made.

The link between better knowledge about sexuality and increased self-esteem was reported by Löfgren-Mårtenson (2012). In the study, young people with LD stated that when they understood what was being taught to them during SRE lessons, they felt their self-esteem increased. In the Levenson-Gingiss and Hamilton's study (1989), SRE teachers working in mainstream schools expressed a belief that it was the most important to teach students "methods to enhance self-esteem" and "interactional skills."

A recommendation not mentioned to my knowledge in previous research, but suggested by several interviewees in this study, was to use humour during sessions, "make it fun" and always start and finish "on a high note." Humour can be beneficial to make students more relaxed and open, reduce embarrassment, make things more memorable and to lift spirits after discussing challenging and difficult topics, such as an abuse.

Another technique that several participants in the sample found helpful was doing research together with students about resources in the local area, where they could go to get information and who could help them on a range of topics. To my knowledge, such an advice was not mentioned in previous studies. A tactic that could be used not just by teachers, but also parents and other professionals was to show individuals websites, where they could find useful, reliable information. It was also recommended that they visit sexual health clinic with people with LD, not only to make them aware of places where they could receive advice or treatment, but also to make them feel more confident about visiting venues like this.

All the above implications require policy makers to make sure that SRE is mandatory from early years and that the recommendations regarding delivery of it to be very clear and non-ambiguous. As mentioned previously, SRE will be compulsory in all schools in England from September 2020. Schools and local authorities need to make sure that appropriate budgets for provision of SRE are allocated. Additional money is required to run groups for parents (whether support orientated or parental advisory panels), to purchase appropriate resources, to pay for the training needed to ensure that teachers feel well prepared and competent to meet their targets and to allow educators to have sufficient personal preparation time.

5.7 Limitations of the Study and Recommendations for Further Research

The main limitation of the study is the fact that the participants involved in it were teachers working with young people (10) and educators (5), who worked with both young and older individuals. This means that the interviewees working with older adults potentially had different experiences to those involved in the education of adolescents. Wilkenfeld and Ballan (2011) compared experiences and attitudes of teachers and instructors working with people with LD in the USA. The major difference they identified in the responses between teachers and instructors was regarding perceptions of their role as sexuality educators. Instructors appeared willing to assume the role of sexuality educator for students with LD. However, the majority of teachers did not view educating students about sexuality as their professional responsibility but defined their roles in a more traditional capacity as authority figures with a specific mission to teach a prescribed core curriculum (Wilkenfeld & Ballan, 2011). There is also a possibility that the tutors who agreed to take part in this research presented more positive and liberal attitudes towards the sexuality of people with LD than those who did not consider participation. In addition, they might have felt more competent and comfortable in their roles, than those who declined to participate.

No questions regarding time in post or qualifications were asked. Recommendations for future research would be to control for socio-demographic data, such as age, professional preparation, or personality traits to ascertain if they have any impact on the views and experiences of the teachers/educators.

Additionally, in relation to one of the main challenges mentioned by interviewees- the heterogeneity of the students, more research is needed to explore how teachers can meet the diverse needs of the pupils, especially those with more severe difficulties, what techniques work, and how to make education more inclusive. This is particularly important in the light of the fact mentioned by several participants that the population of students in special schools seems to be changing and including youngsters with more profound disabilities with those with milder impairments attending mainstream schools.

To conclude, understanding the nature of issues that teachers struggle with can be useful in determining the nature of the support needed and training required. Educators delivering SRE to people with LD face many challenges and should be supported by senior level teams as well as where possible by parents and other professionals involved in the support and care of individuals with LD.

6. Chapter Six

Summary of All Studies

The results of my studies show that the knowledge concerning sexual health and relationships of people with LD is highly variable, from very simplistic, limited mainly to knowledge of body parts, to full awareness of issues related to sex and relationships. The results of Study 1 suggest that there is a strong association between levels of IQ and levels of knowledge about sex and relationships. Participants who reported having some form of sex education scored significantly higher on the SexKen questionnaire than those reporting no formal sex education. The results of my studies suggest that there is no association between age and knowledge and no difference in knowledge between men and women. The study demonstrated that there was strong association between sexual experiences and levels of knowledge about sex and relationships. However, it needs to be acknowledged that the participants in the sample were a very heterogenous group. The age range of the participants was very wide as well as the severity of their disability, which affects generalisations of the findings.

Nearly all the participants (25) in Study 2 had experience of having girlfriend/boyfriend/ partner either at the time of the interview or in the past. Seventy percent of the participants in the study reported having experiences of intimate kissing and 38% of sexual intercourse. Eighty nine percent of the participants, who took part in my study expressed a wish to be in a romantic relationship, 70% wanted to get married and 22% of the participants wanted to be parents. The participants did not report facing barriers or negative attitudes by support providers and families to form relationships and enjoy their privacy. Though again, participants' living arrangements and circumstances, age and the extent of social exclusion differed, which influenced their experiences and makes generalisations difficult.

The quantity of sex-related parent-child communication and parental comfort and ability to have such a discussion are factors that were shown to be related to the perceived sexual health knowledge of children with LD as assessed by parents. Out of the personality factors, only neuroticism was associated with the level of perceived knowledge of the children. The negative correlation between neuroticism and the PLK suggests that parents who are less anxious and more emotionally stable see their children as being more knowledgeable. The results of Study 2 confirm findings of Study 1 that individuals with LD who had sex and relationships education appear to be more knowledgeable. In addition,

children of the participants who had high support needs were assessed by the parents to have lower levels of knowledge.

Teachers and educators who took part in the Study 3 talked about general difficulties when working with people with LD, such as communication, problems with understanding, but also about challenges specific to the subject: sex being a taboo topic, embarrassment, and reluctance of the students and/or parents to discuss it. To pass on as much knowledge as possible and to help the students develop necessary self-protection skills, interviewees developed ways of overcoming the difficulties. They shared their tips, advice and good practice. In addition, due to many restrictions, such as time limits, but also capabilities of their students, teachers had to prioritise what they do and choose what in their opinions learners should know, the most important areas and skills.

6.1 Sexual Health Knowledge

6.1.1 Best and least known areas.

A common theme for all the studies forming this thesis was the assessment of the best and least known areas when it comes to the sexual health knowledge of people with LD, which is a unique element of the thesis as I have been able to assess this from three different perspectives. Table 31 shows topics ranked from the best to the least known by the groups who took part in each study. The percentages indicated by each topic for Study 1 and 2 were calculated by dividing the mean achieved by the participants to the maximum score that could be achieved. With regards to Study 3, the most common answer to the questions about the best and least know topics was that it varied and depended on the student, but some areas were identified. When it comes to the best known areas- each topic listed in the table was mentioned by three participants and the least known points were reported by one teacher each. As it was an open-ended question, the topics mentioned are different from those in Study 1 and 2.

It has to be acknowledged that the results were derived from three unrelated samples and therefore comparisons have to be treated with caution. Apart from the body parts and sexual interaction sections, parent estimates of their child's knowledge were higher than those achieved by the participants in Study 1. This is especially surprising considering that most participants in the Study 1 had mild LD, whilst the majority of the children of the participants in this study had moderate/severe level of disability (83%). As the level of knowledge appears to be associated with the level of functioning and IQ, the expectation was

that the perceived level of knowledge would be lower than the one presented by the participants from Study 1. An explanation could be that the parents who took part in the survey were discussing sex-related topics with their children frequently and were feeling comfortable and confident to do so and as a result of that, as shown by result of Study 2, the knowledge of the children was better. Another explanation is the format of the answers of the on-line survey. As explained in Chapter 4.2.1, adaptations made to the SexKen questionnaire during transformation into an on-line survey meant that potentially it was easier to score higher as there were no open-ended questions and no ambiguous pictures. Szollos and McCabe (1995) compared actual knowledge of people with LD with perception of their paid carers and they found that care staff overestimated the sex and relationships knowledge of their clients (Szollos & McCabe, 1995). The authors did not provide an explanation of the result.

Table 31

The best and least know topics according to participants from all studies

Study 1	Study 2	Study 3
1. Body parts 81%	1. Body parts 78%	*Best*: Body parts (3)
2. Marriage 75%	2. Marriage 76%	Friendship (3)
3. Sexual interaction 55%	3. Homosexuality 61%	Keeping safe (3)
4. Pregnancy, abortion, and childbirth 45%	4. Menstruation 60%	Condoms (3) Staying healthy (3)
5. Contraception 42%	5. Sex 57%	
6. Menstruation 40%	6. Pregnancy, abortion, and childbirth 55%	*Least:* Social awareness, How to become pregnant,
7. STD's 30%	7. Sexual interaction 51%	Mechanics of sex and emotions,
8. Homosexuality 30%	8. Contraception 42%	Consent, Contraception, Relationships,
9. Sex 20%	9. Masturbation 41%	Body parts, STD's,
10. Masturbation 20%	10. STD's 40%	Contraception, Sex, rights and social skills, Sexual intercourse, Tolerance.

The findings suggest that the topic considered as being best known by participants from all studies is body part identification; however, one teacher mentioned it as the least known subject by his students. When it comes to the least known areas, teachers and parents assessed sexually transmitted diseases (STDs) to be unknown by many people with LD and this was born out by the findings of Study 1.

Poor knowledge of STDs could be due to the fact that teachers do not have adequate information about the diseases. Study conducted by Westwood and Mullan (2007) which involved 155 teachers from mainstream secondary schools in the UK, found that 66% of them reported that they either did not have enough or had no information regarding STDs. The study also assessed teachers' knowledge and found it to be generally good, with the exception of knowledge regarding emergency contraception and STDs (Westwood & Mullan, 2007).

Participants from Study 1 scored low on the masturbation section and parents from Study 2 also believed that they children did not possess much knowledge about it, but the topic was not mentioned by any of the participants from Study 3. Two teachers from Study 3 reported contraception as a difficult topic, but the actual knowledge of participants from Study 1 and perceived knowledge of children of participants from Study 2, can be classified as medium.

Homosexuality is an interesting topic as it was found to be one of the least known topics to the participants in Study 1, whilst the perceived knowledge, assessed by parents, about it appeared to be medium. An explanation of these results could be that the parents, who agreed to take part in the sex-related study, presented more positive attitudes towards sex and different types of relationships and felt more comfortable discussing it and, because of that, the perceived level of knowledge of their children was better. In addition, four teachers from Study 3 reported that pupils were not keen to discuss the topic of homosexuality and presented negative attitudes towards same-sex relationships and non-normative sexual behaviours, which could suggest that the knowledge of the students regarding this topic was low.

6.1.2 Sources of information.

When it comes to the sources of sex- related information, thirteen people (48% of participants) from Study 1 reported having sex and relationships education at school and three people were provided with some information on sexual health by their families. Parents of children with LD who took part in Study 2, reported that they provided the information themselves (29.91%), and over one third (35.27%) replied that teachers did it (more than one option could be chosen). When asked whose responsibility it was to provide sex education to people with LD, similar percentages pointed to 'Parents/ Family' (34.38%) and school (30.36%). Participants from Study 3 were not asked about the sources of information.

However, Teacher 8 mentioned in his interview that for some people with LD, media and internet were the main source of information, which could lead to incorrect knowledge and "distorted views" especially if individuals had no capacity to assess an accuracy of what was seen by them.

Nowadays, there appears to be an agreement that in order to increase the effectiveness of education, especially for people with LD, where repetition and consistency are important aspects of learning, a close collaboration between all stakeholders needs to be present. Therefore, schools, parents and support providers need to be involved in formal and informal education.

6.2 Factors Affecting Knowledge

6.2.1 Sex education.

Participants from Study 1 who reported having some form of sex education scored significantly higher on the SexKen questionnaire. Parents of children who participated in SRE assessed them as having higher PLK than those who had little or no sex education. All the teachers and educators who took part in the Study 3 agreed that sex education was very important. According to the participants in the sample, the main reason why it was essential was to help students stay safe. Interviewees were also asked about parental feelings regarding their children's participation in SRE classes. Overall, according to the teachers who took part in Study 3, most parents were happy for their children to take part in sex education and relieved that they did not have to do it themselves. Occurrences of carers withdrawing their children from SRE lessons were rare. However, some people felt anxious about the potential negative consequences of their children being taught about sexual health in the opinion of the educators, who took part in this research.

6.2.2 Age and gender.

The results of Study 1 from this thesis showed no difference in knowledge between men and women. Results from the Study 2 also suggested no difference in the way parents assessed the PLK of their sons and daughters. This result is unexpected considering that a review of the literature regarding communication between parents and children in the general population consistently showed that mothers communicated more with their daughters (DiIorio et al., 2003) and as shown by the results of the Study 2, there was an association between the parent-child communication and perceived level of knowledge. A potential

explanation could be that when it comes to children with disabilities, other factors such as the level of functioning or communication abilities played a more important role than the gender of the child.

The fact that neither age nor gender seems to have an impact on the level of knowledge, was also reported in previous studies (Galea et al., 2004; Konstantareas & Lunsky, 1997; Leutar & Mihokovic, 2007; McGillivray, 1999; Ousley & Mesibov, 1991; Siebielink et al., 2006).

6.2.3 IQ and level of disability.

A strong correlation between the knowledge scores and the IQ was observed in Study 1. The link between the level of functioning of the child and perception of their knowledge by parents is not clear and it depended on the way in which the level of functioning was categorised. No difference in the PLK score was found between children with different levels of functioning categorised by the level of LD, however, the results showed the predicted directions i.e. people with severe LD were assessed to be less knowledgeable that those with mild or moderate. There was a statistically significant difference in the PLK between children who required support for most activities and those who required a few or less hours of support a day, with the children who required less support being assessed by their parents as more knowledgeable.

Nearly half of the teachers (47%) who took part in Study 3 stated that the factor that had the biggest impact on the students' level of knowledge was their cognitive ability, capacity to learn and disability.

6.2.4 Parental factors.

Parental stress, locus of control and personality traits (openness, conscientiousness, agreeableness, and extraversion), apart from neuroticism, do not appear to be associated with the PLK. The negative correlation between neuroticism and the PLK suggests that parents who are less anxious and more emotionally stable see their children as being more knowledgeable. Therefore, it is possible that parents who are less anxious and more emotionally stable, discuss sex and relationships with their children more frequently and with more confidence, and as a result, their children appear to be more knowledgeable.

Parental comfort, ability and the extent of sex-related discussion with their children appear to play important role when it comes to the parental perception of their childrens

knowledge. Parents who reported frequent discussions about sex-related topics reported higher PLK of their children. Family carers who felt comfortable and able to discuss sex-related topics reported higher PLK than those who did not feel comfortable and able to do so.

Having religious beliefs was shown to be related to the PLK. The perceived level of knowledge was greater for children of parents who affiliated with a religion than for those who had no religious preference. No relationship was found between religious activity and the PLK. Parental education and the household income were not linked to PLK in this study.

6.2.5 Sexual experiences and other factors.

Participants from Study 1 who had sexual experiences were more knowledgeable about sex and relationships than those who had not. Parents who took part in study 2 were not asked about the experiences of their children.

Factors that had an impact on the level of knowledge according to the teachers from Study 3, apart from level of functioning, were: access to the internet, parental involvement, quality of education at school, people working with individuals with LD discussing the topic, opportunities to learn, self-esteem, and family environment.

6.3 Sexual Experiences

Nearly all the participants (25) from Study 1 had experience of being in a romantic relationship. The vast majority of participants in my study stated that they would like to be in a relationship (89%) and 70% of the participants (19 people) stated that they would like to get married. Twenty two percent of participants who took part in Study 1 wanted to be parents.

Parents who took part in Study 2 were not asked about experiences of their children. Most teachers, who took part in Study 3, expressed a belief that students' experiences varied significantly: from people who had no sexual experiences to ones that had multiple occurrences of different types of sexual activity. Three participants believed that the sexual experiences of their students were "limited." One teacher stated that pupils would not talk to him about their experiences and therefore he had no means of knowing whether they were sexually active or not. When asked what hopes/needs students did have when it comes to relationships, most teachers replied that the students hoped to be in a loving relationship and had "the same hopes and needs as everyone else."

6.4 The SexKen Questionnaire

During my research, I encountered some issues with the SexKen questionnaire. They are outlined in Chapter 3.5.3. In my thesis, I proposed some initial suggestions regarding the tool and the scoring manual that could be considered in future research or when developing new tools (Chapter 3.5.4 and 3.5.6).

6.5 Discussion

The actual level of sexual health knowledge presented by the participants who took part in Study 1 appears to be comparable to results achieved by the participants in previous studies. The same is true for sexual experiences and experiences of being in a relationship. As the study regarding parental perception of their children's knowledge was unique, results cannot be compared. The experiences of teachers delivering SRE to people with LD, who took part in Study 3 appear to vary from results reported in previous studies. All reported challenges were associated with the characteristics of the students with LD, rather than personal (i.e. anxiety or ambivalence) or institutional barriers (e.g. lack of support from senior members of staff or insufficient training). This could be due to the fact that attitudes towards the sexuality of people with LD are becoming more accepting which leads to less anxiety about the topic. In addition, with the forthcoming changes to the provision of SRE, schools are better prepared for delivery of it. More resources and training programmes are available. What is more, several participants mentioned that the population of the pupils attending special schools appears to be changing with students with less severe disabilities being included in mainstream education with those going to special schools presenting lower levels of functioning.

Overall, the biggest difficulty encountered conducting the research was recruitment. This led to the need to change the project several times. Issues with recruitment were due to two main reasons: the sensitive nature of the research and the location of the University. In the area, there are two large Universities, one of them being rated in the top three of universities in the world with well-established links with the community. Local organisations and individual families of people with LD and ASD are approached with requests to take part in research frequently. As mentioned previously, the main concern expressed by families who did not wish to take part in my research was that participation could lead to an increase in unwanted, sexualised speech and behaviour of the individuals with LD. On an organisational

level, it can be assumed that some establishments, for example schools, refused to support the research in order not to be seen as promoting certain behaviour and attitudes.

When it comes to lessons to be learned for future research regarding recruitment, based on the difficulties faced in this research, two things can be recommended. To address issue with recruitment, it is advisable to reach people who live outside of agglomerations. This applies to potential participants with LD, parents of disabled children and professionals. Many services are operating in rural communities and individuals are not frequently consulted, yet they are happy to share their experiences and voice their opinions. Second piece of advice is to identify groups or forums consisting of people with LD, carers and professionals. Frequently, such groups exist as advisory bodies to the councils or are part of advocacy organisations. Service users who attend such groups can be potentially recruited to take part in research but can also offer a valuable advice regarding the research, for example design. When it comes to concerns of parents and stakeholders considering giving consent for people in their care to take part in sexuality related research, it is advisable to meet with them in person so that potential questions can be answered and apprehension can be alleviated. Benefits and practical implications of the research should be emphasised as well as steps taken to reduce any potential risks.

6.6 Limitations of the Studies

Each study had its own unique limitations, which are discussed in more details in sections 3.6, 4.6 and 5.7. The general, main limitation for all off the studies is that the samples were convenience samples and not necessarily representative of the populations under study. Samples for all studies consisted of participants with broad age ranges, diverse experiences, different support needs and levels of functioning (Study 1 and children of the participants from Study 2). This affects generalisability and transferability of findings. What is more, the three samples were not related in any way to each other which means that the comparisons between samples need to be treated with caution.

In addition, it can be speculated that all the participants who agreed to take part in the studies felt comfortable discussing sex related issues, and as such potentially represented more open and liberal attitudes towards sexuality in general. In addition, parents and teachers who participated in the studies felt more confident in their roles as sex educators.

6.7 Recommendations for Research and Policy

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

Most studies regarding sexual health knowledge and sexual experiences, including mine, concentrate 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, as well as the effects of stigma and social isolation.

Several areas are worth further investigation. Research is particularly needed that explores sexual health issues across the lifespan, including children, adolescents, adults and older adults. 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 used to measure levels of knowledge, with the development of tools that can be used with people who communicate in different ways, other than speech.

This thesis suggests several policy recommendations. Better training and support for teachers is needed to reduce their potential anxiety about delivering sex education. Sexual health education has to be implemented in all schools, as per upcoming law in the UK, it should be tailored to the needs of the learners, and education and support must be available after leaving school. It is clear from previous as well as this research that teaching people with LD is 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. In addition, greater support needs to be given to parents in order to increase their comfort and ability to play the role of sex educators in the lives of their children.

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Appendices

Appendix 1

Anglia Ruskin University

Participant Information Sheet

I am **Magda**, a PhD student from the Anglia Ruskin University in Cambridge.

I am researching what people **know** about **relationships** and sexual health.

I also want to find out what are their **needs, hopes and experiences** when it comes to relationships.

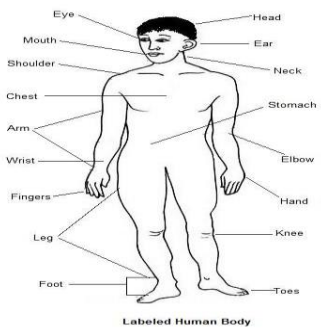
If you are **over 13 years old** and have learning disability,

I would like to ask you **to take part** in my study.

What will happen?

I will ask you to do a **short test**.

Next, I will **ask you questions** about romantic relationships, such as kissing, dating and getting married.



Labeled Human Body

We will talk about different **body parts**.

Some of the questions are about personal things.

I will **tape record** the meeting if you agree.

Where?

You may come to the **University**.

Or I will visit where **you are**.

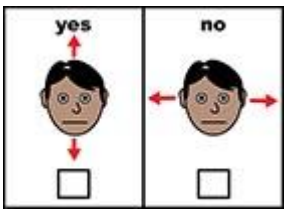
Time taken

The study will take about **1 hour**.

There will be **breaks**.

You can finish the study on **another day** if you like.

Your rights



You do not have to take part.

<u>You can say no.</u>

You can **stop** at any time you want.

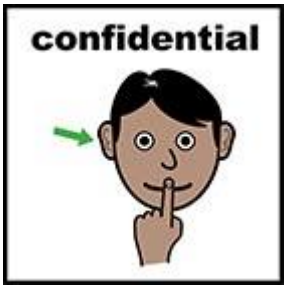
Risk and benefits

Everyone who takes part will receive **£10.00** for his or her time.

The research may **help** other people like you.

Taking part will **not harm** you.

Confidentiality and results



Everything you say will be **confidential**.

If you tell me someone has **hurt** you, I may have to pass this information on.

Results of the research may be written in **papers** and be presented at **talks**.

I may put some of your answers into papers but I **will not** use your **name**.

Questions

Do you have any **questions?**

Contact

Call or text me on

07533 449402

Email: MB1106@student.anglia.ac.uk

Post: Magda Charko

Anglia Ruskin University

Department of Psychology

East Road

Cambridge, CB1 1PT

Appendix 2

Sexuality Knowledge Scale for People with Intellectual Disability SEX KEN- ID

Adapted from the 1994- Fourth Edition of Marita McCabe's SEX KEN-ID

Introduction

This questionnaire/ interview schedule has been adapted from the original version of the SEX KEN-ID (McCabe, 1994). It is designed to be carried out with adults and adolescents with learning disabilities. The adapted questionnaire uses all the knowledge- K, feelings- F, experiences- E and needs- N questions from the SEX KEN-ID scale. Each aspect can be tested separately.

The format has been revised in that all the questions are covered within one interview, rather than in three, as was the case in the original version. In the original format, at the end of each interview, questions relating to the subsequent interview are asked to ascertain if participants have sufficient knowledge to proceed. However, as the questions are not always representative of the subsequent sections and it is not clear how many questions should be answered correctly in order to move to the next part, I suggest that the knowledge is assessed by asking two questions on the topic and not a section (for example condoms and not the whole section on a contraception). If the participant does not appears to possess any knowledge on a topic, after using alternative words and rephrasing, no more questions regarding the topic should be asked.

The changes made by myself to the original questionnaire are highlighted. Four additional questions added by O'Callaghan and Murphy (2002) were kept: "What is oral sex?" "What is foreplay?" "What is anal sex?" and "Can women/girls get pregnant the first time that they have sex?" These were considered to be important aspects of sexual activity, but did not appear in the original version.

Some questions, which were found to be difficult to understand or unclear were removed (i.e. "What is meant by feeling close to someone?" these were crossed out (strikethrough), or rephrased. For example the question: "Can children get pregnant?" was changed to "Can children under the age of 10 get pregnant?"

Instructions

Safeguarding and comfort of the interviewees should be the top priority. Interviewees should be regularly reminded that they have a right to decline to answer the questions and to stop the interview at any point. If the interviewee becomes upset or embarrassed, the interview needs to be stopped.

It is acceptable to rephrase questions if they are not understood or replace terms which are unknown to the interviewees (some suggestions are offered, but the replacement terms will depend on the age of the interviewee/ locality etc.) If after rephrasing the questions, using another terms, the interviewee does not know the answers to two questions regarding one aspect of knowledge, no further questions regarding the activity or items should be asked. For example, if the interviewee is not aware of condoms (after using other terms to replace it), no further questions regarding the knowledge or experiences of using a condom should be asked. It is also acceptable to provide examples. For example, with the question: "What do you do if someone wants to kiss you and you don't want to?" give an example e.g. you are walking down the street and somebody kisses you, what would you do. Examples are provided, but it is acceptable to change them to make them more relevant to the interviewee.

To avoid or minimise situations when interviewees have to remember several options, when the format of the answer is a multiple choice or in the form of a Likert scale in the original scale, I suggest that the question should be read out without the provided options initially and the suggested answers used as prompts when interviewee finds it difficult to answer the question. For example, in relation to the question: "What do you and your female friend(s) do together?", if the interviewee struggles to respond, some or all of the suggested options could be mentioned to aid: "watch TV/videos, play sport, go out, talk, cuddle and kiss, other (please specify)".

In addition, some of the prompt pictures provided with the tool are of poor quality (for example, the picture of the contraceptives) or ambiguous (i.e. pictures of a man and woman touching their bodies). Therefore, it is recommended to prepare pictures representing the same activities or items of a better quality and present them if the interviewees are not clear what the original picture represents.

In the situation when the interviewee provides an answer, which is scored 0, for example replies "Thursday" in response to the question "What is a date?," it is acceptable to ask a follow up/ prompt question, for example: "Can you think of anything else?"

General consent

I want to ask you a number of questions about relationships and sexual health. These questions will ask about what you know, what you have done, and about your feelings. The questions ask for very private information. You can choose if you want to answer these questions. You do not have to answer any of these questions. If you decide not to answer these questions, that is ok. If you decide, you want to stop the interview at any stage, that is ok. Just let me know.

You may not know the answers to some questions. That is quite ok. You may not have experienced some things. That is ok too. I just want to know about you. I will not let anyone else know what you tell me. However, if you tell me about having any sexual experiences that you did not agree to, I will have to tell…….. (specify person).

I will ask you questions on many topics. I will tell you about what we will cover in each section and you can decide whether you want to answer the questions. Remember, it is ok to say that you do not want to take part in the study.

Do you have any questions?

Do you want to take part in the study?

Age_____ Gender_____

FRIENDSHIP

First, there are some questions on friendship. Do you mind answering questions on this topic? If you decide that you do not want to answer any of these questions, that is OK. Just let me know.

1. K What is friendship?

2. N Do you wish you had more female friends?

No, Not At All Slightly More Somewhat More Much More Very Much More

3. E How many close female friends do you have? (If none, go to question 9)

(number _)

4. E In an average week, how often do you spend time with female friends? (make sure that the participant understands the word 'female'; replace if needed with ladies, girls or other; read out the question without the provided options initially; if no answer or "don't know" mention the options listed below; if an answer is different from the options below, for example "not very often", then clarify using the options below)

Almost Never Once a week Twice a week 3-4 Times Every day

5. N Do you wish you could spend more time with your female friends? (read out the question without the provided options initially; if no answer or "don't know" mention the options listed below; if an answer is different from the options below, for example "yes", then clarify using the options below)

No, not at all Slightly More Somewhat More Much More Very Much More

6. F In general, how do you feel about your female friends?(read out the question without the provided options initially; if no answer or "don't know" mention the options listed below; if an answer is different from the options below, for example "ok", then clarify using the options below)

Very Bad Bad Neutral Good Very Good

7. E What do you and your female friend(s) talk about? (~~please tick as appropriate)~~ (read out the question without the provided options initially; if no answer or "don't know" mention the options listed below)

Work/school

People we know

Problems

Hobbies

Our families

Sport

Sex

Other (please specify)

8. E What do you and your female friend(s) do together? (read out the question without the provided options initially; if no answer or "don't know" mention the options listed below)

Watch TV/videos

Play sport

Go out Talk

Cuddle and kiss

Other (please specify)

9. N Do you wish you had more male friends? (read out the question without the provided options initially; if no answer or "don't know" mention the options listed below)

No, Not At All Slightly More Somewhat More Much More Very Much More

10. E How many close male friends do you have? (please make sure that the participant understands the word 'male'; replace if needed with men/ guys or other)

(number _)

11. E In an average week, how much time do you spend with your male friends?(make sure that the participant understands the word 'male'; replace if needed with mates, blokes or

other; read out the question without the provided options initially; if no answer or "don't know" mention the options listed below)

Almost never Once a week Twice a week 3-4 times a week Every day

12. N Do you wish you could spend more time with male friends? (read out the question without the provided options initially; if no answer or "don't know" mention the options listed below; if an answer is different from the options below, for example "yes", then clarify using the options below)

No, Not At All Slightly More Somewhat More Much More Very Much More

13. F In general, how do you feel about your male friends? (read out the question without the provided options initially; if no answer or "don't know" mention the options listed below; if an answer is different from the options below, for example "ok", then clarify using the options below)

Very bad Bad Neutral Good Very Good

14. E What do you and your male friend(s) talk about? (please tick as appropriate) (read out the question without the provided options initially; if no answer or "don't know" mention the options listed below)

Work/school

People we know

Problems

Hobbies

Our families

Sport

Sex

Other (please specify)

15.E What do you and your male friend(s) do together? (please tick as appropriate) (read out the question without the provided options initially; if no answer or "don't know" mention the options listed below)

Watch TV/videos

Play sport

Go out

Talk

Cuddle and kiss

Other (please specify)

16. E Do you have a special boyfriend, girlfriend or partner?

Yes No (if no go to question 22)

17. E Is this person male or female? (replace the terms if unknown)

Male Female(please tick as appropriate)

18. E Approximately how long have you been with him or her? _____

19. E In an average week, how often do you see this person? (read out the question without the provided options initially; if no answer or "don't know" mention the options listed below; if an answer is different from the options below, for example "not very often", then clarify using the options below)

Almost Never Once a week Twice a week 3-4 times a week Every day

20. N How often would you like to see this person? (read out the question without the provided options initially; if no answer or "don't know" mention the options listed below; if an answer is different from the options below, for example "yes", then clarify using the options below)

Almost Never Once a week Twice a week 3-4 times a week Every day

21. F How do you feel about your relationship with this person? (read out the question without the provided options initially; if no answer or "don't know" mention the options listed below; if an answer is different from the options below, for example "ok", then clarify using the options below)

Very bad Bad Neutral Good Very Good

22. E When was the last time you had a boyfriend/girlfriend, partner?

Never A Few weeks ago A Few months ago A Year ago Many Years ago

23. F Would you like to have a boyfriend/girlfriend, partner? (read out the question without the provided options initially; if no answer or "don't know" mention the options listed below; if an answer is different from the options below, for example "yes", then clarify using the options below)

No, Not At All Probably Not Unsure Probably yes Yes, definitely

DATING AND INTIMACY

I am now going to ask you some questions on dating and intimacy. Do you mind answering questions on this topic? If you decide that you do not want to answer any of these questions, that is OK.

24. K What is a date? (If the answer given is not in line with the model answer sheet, for example, the interviewee says: "It's Thursday," ask prompt question: Can you think of anything else?

25. N Would you like to know more about dating? (read out the question without the provided options initially; if no answer or "don't know" mention the options listed below; if an answer is different from the options below, for example "yes", then clarify using the options below)

No, Not At All Slightly More Somewhat More Much More Very Much More

26. E Have you ever been out on a date or gone out with a boyfriend/girlfriend? (please tick as appropriate)

Yes No

27. E What did you do? (please tick as appropriate) (read out the question without the provided options initially; if no answer or "don't know" mention the options listed below)

Pictures

Dinner

Beach

Walk

Dance

Have sex

Other (please specify)

27. F Do you think you would like to go out with a girlfriend/ boyfriend/ partner? (read out the question without the provided options initially; if no answer or "don't know" mention the options listed below)

No, not at all A little Somewhat A lot Yes, definitely

28. F Is there anyone you would like to go out with?

Yes No

29. F What would you like to do? (read out the question without the provided options initially; if no answer or "don't know" mention the options listed below)

Pictures

Dinner

Beach

Walk

Dance

Have sex

Other (please specify)

30. N Would you like to go on more dates? (read out the question without the provided options initially; if no answer or "don't know" mention the options listed below; if an answer is different from the options below, for example "yes", then clarify using the options below)

No, Not At All Slightly More Somewhat More Much More Very Much More

~~31. K What is meant by feeling close to someone?~~

~~32. N Would you like to know more about feeling close to people?~~

No, Not At All Slightly More Somewhat More Much More Very Much More

33. E ~~Have you ever felt really close to someone?~~

Never Almost never Sometimes Often Very often

34. F ~~Do you know anyone you would like to be close to, or not?~~

Yes No

35. F ~~Do they know you feel like this?~~

Yes No

36. F ~~What would you like to do with them?~~

~~Go out together~~

~~Talk~~

~~Watch TV~~

~~Play Sport~~

~~Have Sex~~

~~Other (please specify)~~

37. N ~~Would you like to be close to someone~~?

~~No, Not At All Slightly More Somewhat More Much More Very Much More~~

38. E Have you ever been in love or loved someone, or not?

Yes No

MARRIAGE

I am now going to ask you some questions on marriage. Do you mind answering questions on this topic? If you decide that you do not want to answer any of these questions, that is OK. Just let me know.

39. K What is marriage?

40. K What is this a picture of? (See Figure l) (present a variety of pictures representing people of different abilities, races etc. and different cultures if the answers is unknown; if the

answer given is not in line with the model answer sheet, for example, the interviewee says: "people holding hands" ask prompt question: "Can you think of anything else?"

41. F How do you feel about getting married? (read out the question without the provided options initially; if no answer or "don't know" mention the options listed below; if an answer is different from the options below, for example "ok", then clarify using the options below)

Very bad Bad Neutral Good Very Good

42. N Would you like to know more about marriage and being married? (read out the question without the provided options initially; if no answer or "don't know" mention the options listed below; if an answer is different from the options below, for example "ok", then clarify using the options below)

No, Not At All Slightly More Somewhat More Much More Very Much More

43. F Who gets married?

44. F Why do people get married?

45. F Does everyone have to get married?

Yes No

46. F Why/why not?

47. F If people want to have sex, should they get married?

Yes No

48. F Why/why not?

49. F If people want to have a baby, should they get married, or not?

50. F Why/why not?

51. F If people get married, do they have to have a baby?

Yes No

52. F Why/why not?

53. F Do you want to get married, or not?

54. F Why/why not?

BODY PART IDENTIFICATION

I am now going to ask you some questions about body part identification. Do you mind answering questions on this topic? If you decide that you do not want to answer any of these questions, that is OK. Just let me know.

55. K Which is the woman and which is the man? Please label figure 2.

56. K Which is the man and which is the woman? Please label figures 3&4.

On the Male: (start with the sex of the interviewee)

57. K a) Label his eyes

b) What are they used for? What can you do with your eyes?

58. K a) Label his nose

b) What is it used for?

59. K a) Label his leg

b) What is it used for?

60. K a) Label his navel or his belly button

61. K a) Label his buttocks or his bottom

b) What is it used for?

62. K a) Label his feet

b) What are they used for?

63. K a) Label his penis (replace with another term if not known: willie/ winkle/ any other locally used words or slang)

b) What is it used for?

64. K Label his chest

65. K Label his ankles

On the female:

66. K a) Label her arm

b) What is it used for?

67. K Label her shoulder

68. K a) Label her mouth

b) What is it used for?

69. K a) Label her breasts (replace with another term if not known: tits/ boobs/ any other locally used words or slang)

b) What are they used for?

70. K a) Label her neck

b) What is it used for?

71. K Label her hips

72. K a) Label her nipples

b) What are they used for?

73. K a) Label her hands

b) What are they used for?

74. K a) Label her vagina (replace with another term if not known: front bottom/ lady parts/ any other locally used words or slang)

b) What is it used for?

75. K Label her back

SEX EDUCATION (In the original version, the section is combined with 'sex'; in this version they are split)

I would like to ask you some questions about sex education. Do you mind answering questions on this topic? If you decide that you do not want to answer any of these questions, that is OK. Just let me know.

76. E Have you ever had any sex education? That is, has anyone provided you with information on sex? (for example on contraception, safe sex, masturbation, sexual acts, pregnancy, birth control)

Yes No

77. E Who gave you this information? (please tick as appropriate)

Parents

Brothers/sisters

Friends

Teachers/ learnt at school

Other (please specify)

78. F How useful was this sex education? (read out the question without the provided options initially; if no answer or "don't know" mention the options listed below; if an answer is different from the options below, for example "ok", then clarify using the options below)

Not at all A little bit useful Useful Very useful Extremely useful

79. F How important is sex education to you? (read out the question without the provided options initially; if no answer or "don't know" mention the options listed below; if an answer is different from the options below, for example "ok", then clarify using the options below)

Not at all A little bit important Important Very important Extremely important

80. N Would you like more sex education? (read out the question without the provided options initially; if no answer or "don't know" mention the options listed below; if an answer is different from the options below, for example "ok", then clarify using the options below)

No, Not At All Slightly More Somewhat More Much More Very Much More

SEX (In the original version, the section is combined with the 'sex education')

I would like to ask you some questions on sex. Do you mind answering questions on this topic? If you decide that you do not want to answer any of these questions, that is OK. Just let me know.

81. K What is meant by having sex? (replace with another term if not known: making love/ shagging/ any other locally used words or slang OR Rephrase the question)

82. F How do you feel about having sex? (read out the question without the provided options initially; if no answer or "don't know" mention the options listed below; if an answer is different from the options below, for example "ok", then clarify using the options below)

Very bad Bad Neutral Good Very good

83. E How often do you talk to members of your family about sex? (read out the question without the provided options initially; if no answer or "don't know" mention the options listed below; if an answer is different from the options below, then clarify using the options below)

Never Once A few times Often Very Often

84. E How often do you talk to your friends about sex? (read out the question without the provided options initially; if no answer or "don't know" mention the options listed below; if an answer is different from the options below, then clarify using the options below)

Never Once A few times Often Very Often

85. E How often do you think about sex? (read out the question without the provided options initially; if no answer or "don't know" mention the options listed below; if an answer is different from the options below, then clarify using the options below)

Almost never Once a month Every week Daily Several times a day

86. E How often would you like to have sex?

Almost never Once a month Every week Daily Several times a day

87. F Is it embarrassing to talk about sex? (read out the question without the provided options initially; if no answer or "don't know" mention the options listed below; if an answer is different from the options below, then clarify using the options below)

No, not at all A little bit embarrassing Embarrassing Very embarrassing Extremely embarrassing

88. N Would you like to talk more about sex? (read out the question without the provided options initially; if no answer or "don't know" mention the options listed below)

No, Not At All Slightly More Somewhat More Much More Very Much More

89. E How often do you have sex? (read out the question without the provided options initially; if no answer or "don't know" mention the options listed below)

Almost never Once a month Every week Daily Several times each day

90. N Do you get enough privacy where you live? (read out the question without the provided options initially; if no answer or "don't know" mention the options listed below)

Never Almost Never Sometimes Usually Always

91. F How important is privacy to you? (read out the question without the provided options initially; if no answer or "don't know" mention the options listed below)

Not at all important A little bit important Important Very important Extremely important

MENSTRUATION

I am now going to ask you some questions on menstruation. Do you mind answering questions on this topic? If you decide you do not want to answer any of the questions, that is OK. Just let me know.

92. K What is menstruation or periods?

93. F How do you feel about menstruation or having periods? (read out the question without the provided options initially; if no answer or "don't know" mention the options listed below)

Very bad Bad Neutral Good Very good

94. N Would you like to know more about menstruation or periods? (read out the question without the provided options initially; if no answer or "don't know" mention the options listed below)

No, Not At All Slightly More Somewhat More Much More Very Much More

95. K Why does a woman have a period?

96. K How often does a woman have a period?

97. K Do men have periods?

Yes No

Q 98- 103 FEMALES ONLY

98. E Do you have periods?

Yes No

99. F How do you feel about menstruation or having periods?

Very bad Bad Neutral Good Very good

100. E Did anyone explain your periods to you before they started?

Yes No

101. K What do you do when you get your period?

102. K Do you know when your period is due or not?

103. K What would you do if your period didn't come?

(For example, see or tell someone. Who?)

104. K ~~When a woman has her period does the blood come from the same hole where the urine or wee comes out?~~

Yes No

Rephrased to:

Does a woman's period blood come from the same hole as urine?

Or

Does period blood and urine leave the body from the same place?

Yes No

105. K Figure 5. What are these? (Replace with a good quality picture of the same items if the interviewee finds difficult to recognise them)

106. K What are they for?

107. K Can you tell me how to use them?

SEXUAL INTERACTION

Now I am going to ask you some questions on sexual interaction. Do you mind answering questions on this topic? In this section, there are some drawings of people without any clothes on. You do not have to see these pictures. Please tell me now if you don't want to see these. If you feel uncomfortable with the questions or pictures at any time, please tell me. You don't have to answer the questions (added by O'Callaghan and Murphy, 2002).

108. E Have you ever held hand with anyone? (read out the question without the provided options initially; if no answer or "yes/no", establish the frequency using the options listed below)

Never Almost Never Sometimes Once Very often

109. F How would you feel about holding hands? (read out the question without the provided options initially; if no answer or "don't know" mention the options listed below)

Very bad Bad Neutral Good Very good

110. K What is this a picture of? What are they doing? See Figure 6

(If the answer given is not in line with the model answer sheet, for example, the interviewee says: "people close" ask prompt question: "Can you think of anything else?"

111. E Have you hugged someone like that? (read out the question without the provided options initially; if no answer or "yes/no", establish the frequency using the options listed below)

Never Almost Never Sometimes Once Very often

112. F How would you feel about being hugged like that? (read out the question without the provided options initially; if no answer or "don't know" mention the options listed below)

Very bad Bad Neutral Good Very good

113. F Who would you hug like that? (i.e. Relative, friend, work colleague)

114. K What is this a picture of? What are they doing? See Figure 7

(If the answer given is not in line with the model answer sheet, for example, the interviewee says: "people close" ask prompt question: "Can you think of anything else?"

115. E Have you hugged someone like that? (read out the question without the provided options initially; if no answer or "yes/no", establish the frequency using the options listed below)

Never Almost Never Sometimes Once Very often

116. F Would you like to hug someone without any clothes on? (read out the question without the provided options initially; if no answer or "don't know" mention the options listed below)

No, not al all Probably not Unsure Probably yes Yes, definitely

117. F Would you like to be kissed? (read out the question without the provided options initially; if no answer or "don't know" mention the options listed below)

No, not al all Probably not Unsure Probably yes Yes, definitely

118. E Have you kissed anyone on the lips, or not? If yes: How many times?

Never Almost Never Sometimes Once Very often

119. E Who have you kissed? (read out the question without the provided options initially; if no answer or "don't know" mention the options listed below)

Boyfriend/ Girlfriend

Partner

Friend

Relative

Someone at work

Other (please specify)

120. K What is this a picture of? What are they doing? See Figure 8

(If the answer given is not in line with the model answer sheet, for example, the interviewee says: "people blowing" ask prompt question: "Can you think of anything else?"

121. E Have you kissed anyone on the lips in a sexy way? (read out the question without the provided options initially; if no answer or "don't know" mention the options listed below)

Never Almost Never Sometimes Once Very often

Females only:

122. E Has anyone touched or kissed your breast? (read out the question without the provided options initially; if no answer or "don't know" mention the options listed below)

Never Almost Never Sometimes Once Very often

123. F How would you feel about having your breast touched or kissed? (read out the question without the provided options initially; if no answer or "don't know" mention the options listed below)

Never Almost Never Sometimes Once Very often

124. E Has anyone touched or kissed your vagina? (replace with another term if not known i.e. term used by the interviewee/ front bottom/ any other locally used word or informal term; read out the question without the provided options initially; if no answer or "don't know" mention the options listed below)

Never Almost Never Sometimes Once Very often

125. F How would you feel about having your vagina touched or kissed? (replace with another term if not known i.e. term used by the interviewee/ front bottom/ any other locally used word or informal term; read out the question without the provided options initially; if no answer or "don't know" mention the options listed below)

Never Almost Never Sometimes Once Very often

Males only (next 2 questions)

126. E Has anyone touched or kissed your penis? (replace with another term if not known i.e. term used by the interviewee/ willie/ any other locally used word or informal term; read out the question without the provided options initially; if no answer or "don't know" mention the options listed below)

Never Almost Never Sometimes Once Very often

127. F How would you feel about having your penis touched or kissed? (replace with another term if not known i.e. term used by the interviewee/ willie/ any other locally used word or informal term; read out the question without the provided options initially; if no answer or "don't know" mention the options listed below)

Never Almost Never Sometimes Once Very often

128. K What is sexual intercourse? (replace with another term if not known i.e. term used by the interviewee/ sex/ making love/ any other locally used word or informal term)

129.K What is this a picture of? What are they doing? See Figure 9

(If the answer given is not in line with the model answer sheet, for example, the interviewee says: "people sleeping" ask prompt question: "Can you think of anything else?")

130. F How would you feel about having sexual intercourse? (replace with another term if not known i.e. term used by the interviewee/ sex/ making love/ any other locally used word or informal term; read out the question without the provided options initially; if no answer or "don't know" mention the options listed below)

Very bad Bad Neutral Good Very good

131. N Do you need more information about sexual intercourse? (read out the question without the provided options initially; if no answer or "don't know" mention the options listed below)

No, not at all Slightly more Somewhat more Much more Very much more

132. E Have you had sexual intercourse? (replace with another term if not known i.e. term used by the interviewee/ sex/ making love/ any other locally used word or informal term; read out the question without the provided options initially; if no answer or "don't know" mention the options listed below)

Never Almost Never Sometimes Once Very often

133. K What does it mean to have an orgasm or to come?

134. K Can a man have an orgasm? (replace with another term if not known i.e. term used by the interviewee/ to come/ any other locally used word or informal term)

Yes No

135. K Can a woman have an orgasm? replace with another term if not known i.e. term used by the interviewee/ to come/ any other locally used word or informal term)

Yes No

136. K What happens when a man has an orgasm? replace with another term if not known i.e. term used by the interviewee/ to come/ any other locally used word or informal term)

137. K What happens when a woman has an orgasm? replace with another term if not known i.e. term used by the interviewee/ to come/ any other locally used word or informal term)

138. K What is ejaculation? (replace with another term if not known i.e. term used by the interviewee/ spurt/ any other locally used word or informal term)

139. K What is semen for? (replace with another term if not known i.e. term used by the interviewee/ cum/ any other locally used word or informal term)

140. K How much semen does it take to get a girl/woman pregnant? (replace with another term if not known i.e. term used by the interviewee/ cum/ any other locally used word or informal term)

Additional. What is oral sex? (Additional questions added by O'Callaghan & Murphy, 2002)

Additional. What is foreplay?

Additional. What is anal sex?

If no experience of sexual intercourse go to Q143

141. E Do you come or have an orgasm when you have sexual intercourse? (read out the question without the provided options initially; if no answer or "don't know" mention the options listed below)

Never Almost never Sometimes Frequently Always

142. E Can you tell me about any different positions you have used for sexual intercourse?

143. E Have you had anal sex?

Yes No

144. F How would you feel about having anal intercourse? (read out the question without the provided options initially; if no answer or "don't know" mention the options listed below)

Very bad Bad Neutral Good Very good

145. F Is it all right to have sexual contact with everyone? (read out the question without the provided options initially; if no answer or "don't know" mention the options listed below)

No, not al all Probably not Unsure Probably yes Yes, definitely

146. F Who would you like to have sexual contact with?

147. K Where do you do any of these things? [Have sexual intercourse/ orgasm] (read out the question without the provided options initially; if no answer or "don't know" mention the options listed below)

My bedroom (please tick as appropriate)

Lounge room

TV room

Toilet

Anywhere

Other (please state)

Somewhere private

148. K Where do other people do these things? (read out the question without the provided options initially; if no answer or "don't know" mention the options listed below)

Their bedroom(please tick as appropriate)

Lounge room

TV room

Toilet

Anywhere

Other (please state)

Somewhere private

149. K Where is it OK to do these things? (read out the question without the provided options initially; if no answer or "don't know" mention the options listed below)

Bedroom

Lounge room

TV room

Toilet

Anywhere

Somewhere private

150. K What do you do if someone wants to kiss you and you don't want to? (if the interviewee does not know the answer, give an example e.g. your work colleague wants to kiss you)

What do you do if someone wants to have sexual contact with you and you don't want to? (Question was split, as the original one was too long; give an example if the interviewee does not know the answer, for example "a stranger wants to touch your private parts and you don't want him/her to do it")

151. K What do you do if someone does kiss you and you don't want them to? (if the interviewee does not know the answer, give an example e.g. you are walking down the street and somebody kisses you)

What do you do if someone does have sexual contact with you and you don't want them to? (Question was split, as the original one was too long; if the interviewee does not know the answer, give an example e.g. you are shopping and somebody touches your breast/ penis)

152. K Can you say "no" to someone who wants to kiss you or have sexual contact with you?

Yes No (please tick as appropriate)

153. K How would you say "no"? Describe what you would do.

154. K Who should decide about whether you have sex with someone or not?

155. F Why should this person decide? (If not the interviewee in response to the above question; in the original version: If someone other than you should decide, why should this person decide?)

156. N Would you like to know more about unwanted sexual contact? (read out the question without the provided options initially; if no answer or "don't know" mention the options listed below)

No, not at all Slightly more Somewhat more Much more Very much more

157. E Are you having sexual contact with anyone at the moment? (read out the question without the provided options initially; if no answer or "don't know" mention the options listed below)

No Occasionally Sometimes Often Very often

158. F Do you see yourself as being sexually attractive? (read out the question without the provided options initially; if no answer or "don't know" mention the options listed below)

No, not al all Probably not Unsure Probably yes Yes, definitely

CONTRACEPTION

Now I am going to ask you some questions on contraception. Do you mind answering questions on this topic? If you decide that you do not want to answer any of these questions, that is OK. Just let me know.

159. K What is contraception or birth control?

160. N Would you like to know more about contraception or birth control? (read out the question without the provided options initially; if no answer or "don't know" mention the options listed below)

No, not at all Slightly more Somewhat more Much more Very much more

161. K What is a condom? (replace with another term if not known i.e. term used by the interviewee/ rubber/ Durex/ any other locally used word or informal term)

162. K Figure 10 What is this a picture of? (replace with a good quality picture; if the answer given is not in line with the model answer sheet, for example, the interviewee says: "chewing gum" ask prompt question: "Can you think of anything else?"

163. K What is a condom for? What does it do? (replace with another term if not known i.e. term used by the interviewee/ rubber/ Durex/ any other locally used word or informal term)

164. K Describe how you put on a condom. (replace with another term if not known i.e. term used by the interviewee/ rubber/ Durex/ any other locally used word or informal term)

165. F How do you feel about using condom? (read out the question without the provided options initially; if no answer or "don't know" mention the options listed below)

Very bad Bad Neutral Good Very good

166. E Do you ever use a condom? (read out the question without the provided options initially; if no answer or "don't know" mention the options listed below)

Never had sex Never use a condom Almost never use a condom
Sometimes use a condom Usually use a condom Always use a condom

167. E Whose responsibility is it to provide a condom for sexual intercourse? (rephrased by O'Callaghan and Murphy, 2002; in the original version: Who usually provides the condom?)

168. K If you wanted to get a condom, what would you do?

169. K Can you name any other things you can use for birth control?

170. K Figure 11 What is this a picture of? (replace with a good quality picture; if the answer given is not in line with the model answer sheet, for example, the interviewee says: “tablets” ask prompt question: “Can you think of anything else?”

171. K What are they used for?

172. E Have you or your partner used any of these, or not?

Yes No

173. E Show me which one(s).

174. E Have you used any other kind of birth control that we have not talked about?

Yes No

175. E What have you used?

Sterilization

Depo provera

Withdrawal

Other (please specify)

176. E Are you or your partner using any kind of birth control at the moment

Yes No

If no, move to the next section; if yes, continue

177. E What are you using?

Pill

Condom

IUD

Diaphragm

Sterilization

Withdrawal

Implant

Other (please specify)

PREGNANCY, ABORTION AND CHILDBIRTH.

Now I am going to ask you some questions on pregnancy, abortion and childbirth. Do you mind answering questions on this topic? If you decide that you do not want to answer any of these questions, that is OK. Just let me know.

178. K What is pregnancy? What does it mean to be pregnant?

179. K Figure 12 What is this a picture of? (If the answer given is not in line with the model answer sheet, for example, the interviewee says: "fat lady" ask prompt question: "Can you think of anything else?"

180. N Would you like to know more about pregnancy? (read out the question without the provided options initially; if no answer or "don't know" mention the options listed below)

No, not at all Slightly more Somewhat more Much more Very much more

181. F (Split the question according to the sex of the interviewee)

Females: How do you feel about becoming pregnant?

Males: How do you feel about making someone pregnant?

Very bad Bad Neutral Good Very good

182. K How does a woman get pregnant?

Additional Q (added by O'Callaghan and Murphy, 2002).

Can women/girls get pregnant the first time that they have sex?

Yes No

183. K Can you have sex without the woman getting pregnant?

Yes No (please tick as appropriate)

184. K How do you stop the woman getting pregnant?

185. K Does the woman still get her period if she is pregnant?

Yes No

186. K Can a woman have a baby without getting pregnant?

Yes No

187. K How long is a pregnancy? How long does the baby stay inside the mother?

188. K How is a baby born?

189. K Figure 13. What is this a picture of? What is happening? (If the answer given is not in line with the model answer sheet, for example, the interviewee says: "woman lying on bed" ask prompt question: "Can you think of anything else?"

190. F (Split the question according to the sex of the interviewee; in the original version, as one question; read out the question without the provided options initially; if no answer or "don't know" mention the options listed below)

Females: How would you feel about giving birth?

Males: How would you feel about being present while your partner has a baby?

Very bad Bad Neutral Good Very good

191. N Would you like to know more about childbirth? (read out the question without the provided options initially; if no answer or "don't know" mention the options listed below)

No, not at all Slightly more Somewhat more Much more Very much more

192. K Does the baby come out of the same hole as the blood when a woman has her period, or not?

Yes No (please tick as appropriate)

193. E Have you ever had children? (in the original version, question aimed at females only)

194. K Can men get pregnant?

Yes No

195. K Do children under the age of 10 get pregnant? (rephrased by O'Callaghan and Murphy, 2002; in the original version: Do children get pregnant?)

196. E Females only: Have you ever been pregnant?

Yes No

197. K What does a woman do if she gets pregnant and doesn't want the baby?

198. K What is an abortion? replace with another term if not known i.e. term used by the interviewee/ termination/ any other locally used word or informal term)

If don't know, move to the next section; if do know, continue:

199. F (Split the question according to the sex of the interviewee; in the original version, as one question; read out the question without the provided options initially; if no answer or "don't know" mention the options listed below)

Females: How would you feel about having an abortion?

Males: How would you feel about your partner having an abortion?

Very bad Bad Neutral Good Very good

200. E Females only: Have you ever had an abortion?

Yes No

SEXUALLY TRANSMITTED DISEASES.

Now I am going to ask you some questions on sexually transmitted diseases (also known as STIs or STDs). Do you mind answering questions on this topic? If you decide that, you do not want to answer any of these questions that is OK. Just let me know.

200. K What is a sexually transmitted disease?

201. N Would you like to know more about sexually transmitted disease?

No, not at all Slightly more Somewhat more Much more Very much more

202. K Can you name any sexually transmitted diseases? Please list them (Rephrased by O'Callaghan and Murphy, 2002; in the original version: How many types of STIs have you heard of?)

203. F How would you feel about catching a sexually transmitted disease?

Very bad Bad Neutral Good Very good

204. K How do you catch sexually transmitted diseases?

205. K How can you tell if you have a sexually transmitted disease?

206. K Should you tell anyone if you think you have a sexually transmitted disease or not?

Yes No (please tick as appropriate) '

If no, go to Q208

207. K Who should you tell?

208. K Should you have sexual intercourse if you think you have a sexually transmitted disease?

Yes No (please tick as appropriate)

209. K Why/why not?

210. E Have you ever had a sexually transmitted disease?

Yes No

If no, go to Q212

211. E What did you do about it?

212. F Are you concerned/ worried about getting a sexually transmitted disease? (read out the question without the provided options initially; if no answer or "don't know" mention the options listed below)

No, not at all worried Slightly worried Somewhat worried Very worried Extremely worried

213. K What is AIDS? What actually is it?

214. K What happens to you if you get AIDS?

215. N Would you like to know more about AIDS? (read out the question without the provided options initially; if no answer or "don't know" mention the options listed below)

No, not at all Slightly more Somewhat more Much more Very much more

216. F How do you feel about getting AIDS?

Very bad Bad Neutral Good Very good

217. K What is the best way to stop getting AIDS?

218. F Are you concerned/ worried about getting AIDS? (read out the question without the provided options initially; if no answer or "don't know" mention the options listed below)

No, not at all worried Slightly worried Somewhat worried Very worried Extremely worried

MASTURBATION.

Now I am going to ask you some questions on masturbation. Do you mind answering questions on this topic? If you decide that you do not want to answer any of these questions, that is OK. Just let me know.

219. K What is masturbation? (Changed the order of the questions. Ask this first to establish if familiar with the term and activity; rephrase the word to other term used by interviewee/ playing with yourself/ wanking/ other word used locally)

220. K *Figure 14* What are these pictures of? What are they doing? (replace with better quality drawing/ picture if neccessary; if the answer given is not in line with the model answer sheet, for example, the interviewee says: “breast examination” ask prompt question: “Can you think of anything else?”)

221. F How do you feel about doing these things? (read out the question without the provided options initially; if no answer or “don’t know” mention the options listed below)

Very bad Bad Neutral Good Very good

222. E Do you ever touch or stroke yourself like this? (read out the question without the provided options initially; if no answer or “don’t know” mention the options listed below)

Almost never Once a month Once a week Daily More than once daily

223. K *Figure 15* What are these pictures of? What are they doing? (replace with better quality picture/ drawing; if the answer given is not in line with the model answer sheet, for example, the interviewee says: “people sleeping” ask prompt question: “Can you think of anything else?”)

224. F How do you feel about masturbating (rephrase the word to other term used by interviewee/ playing with yourself/ wanking/ other word used locally; read out the question without the provided options initially; if no answer or “don’t know” mention the options listed below)

Very bad Bad Neutral Good Very good

225. E How often do you masturbate (or other word known to the interviewee)? (read out the question without the provided options initially; if no answer or “don’t know” mention the options listed below)

Almost never Once a month Once a week Daily More than once daily

If almost never, go to Q229

226. E What do you do when you masturbate (or other word known to the interviewee)?

227. E Where do you usually masturbate (or other word known to the interviewee)? (read out the question without the provided options initially; if no answer or "don't know" mention the options listed below)

My bedroom

Lounge

TV room

Toilet

Anywhere

Other

228. E Do you come or have an orgasm when you masturbate (or other word known to the interviewee)? (read out the question without the provided options initially; if no answer or "don't know" mention the options listed below)

Never Almost never Sometimes Usually Always

229. N Would you like to know more about masturbation (or other word known to the interviewee)? (read out the question without the provided options initially; if no answer or "don't know" mention the options listed below)

No, not at all Slightly more Somewhat more Much more Very much more

230. F Is it OK to masturbate, or not? (or other word known to the interviewee)

Yes No

231. F If somebody wants to masturbate (or other word known to the interviewee) where should they do this? (read out the question without the provided options initially; if no answer or "don't know" mention the options listed below)

Lounge

TV room

Bathroom

Bedroom

Other (please specify)

232. E Are you able to masturbate (or other word known to the interviewee) where you live? (read out the question without the provided options initially; if no answer or "don't know" mention the options listed below)

Never Almost never Sometimes Usually Always

233. F Is it still alright to masturbate (or other word known to the interviewee) if you have a sexual partner? (read out the question without the provided options initially; if no answer or "don't know" mention the options listed below)

No, not at all Probably not Unsure Probably yes Yes, definitely

234. F Do you wish you could masturbate (or other word known to the interviewee) more often? (read out the question without the provided options initially; if no answer or "don't know" mention the options listed below)

No, not at all Probably not Unsure Probably yes Yes, definitely

HOMOSEXUALITY (SAME SEX RELATIONSHIP).

Now I am going to ask you some questions on homosexuality (same-sex relationships). Do you mind answering questions on this topic? If you decide that you do not want to answer any of these questions, that is OK. Just let me know.

235. K What is homosexuality? (if term not known, replace with different one i.e. same sex relationships/ gay or lesbian relationship/ any other term known to the interviewee)

236. F How would you feel about engaging in homosexual behaviour? (read out the question without the provided options initially; if no answer or "don't know" mention the options listed below)

Very bad Bad Neutral Good Very good

237. N Would you like to know more about homosexuality (or other word known to the interviewee)? (read out the question without the provided options initially; if no answer or "don't know" mention the options listed below)

No, not at all Slightly more Somewhat more Much more Very much more

238. E Have you ever had a sexual experience with someone of your own sex? (read out the question without the provided options initially; if no answer or "don't know" mention the options listed below)

No Once A couple of times Often Very often

If no, go to Q242

239. F How did you feel when you were with this person? (read out the question without the provided options initially; if no answer or "don't know" mention the options listed below)

Very bad Bad Neutral Good Very good

240. F Would you do it again? (read out the question without the provided options initially; if no answer or "don't know" mention the options listed below)

Never Probably not Unsure Probably Yes, definitely

241. F Why/ Why not?

242. N Would you like to have sexual contact with someone of your own sex? (read out the question without the provided options initially; if no answer or "don't know" mention the options listed below)

No, not at all Probably not Unsure Probably yes Yes, definitely

243. F Are you homosexual (or other word known to the interviewee)?

No, not at all Probably not Unsure Probably yes Yes, definitely

244. F ~~What made you decide this?~~ Was removed as it can be seen as offensive

THANK YOU!

Appendix 3

Sexuality Knowledge Scale For People with Intellectual Disability Sex- Ken- ID

MODEL ANSWER SHEET by O'Callaghan and Murphy (2002)

FRIENDSHIP

1. What is friendship?

2 points- to trust, choose to spend time with someone, to confide in, to share, to go out with someone (must mention at least two of these)

1 point- to spend time with someone, or to trust someone, be friends forever (i.e.one of the statements)

0 points- they are mates or go out or don't know

DATING AND INTIMACY

24. What is a date?

2 - attracted to a partner and going out with them (i.e. for a meal, to the cinema); partner of either sex, going out on a romantic date, the specification of place or date

1 - going out (romantic) with someone of the opposite sex or same sex or description of where one might go on a date

0- going out, with no specification of with whom or of romantic connotations, or a date as in the day, month, year etc.

31. What is meant by feeling close to someone?

2 - feeling attracted to someone and/or being able to trust/ confide in someone and/or enjoying being with someone- at least 2 of the 3

1 – you like someone or trust confide in or feels nice to be with/ they're important,

0 - sitting near someone, love

MARRIAGE

39. What is marriage?

2 - mention of vows + ceremony/ wedding + commitment to partner + ring (at least 2 of these mentioned)

1 - mention of commitment to partner for life OR wedding/ceremony OR buying of ring OR vows (1 of these mentioned)

0 - getting together/ no answer/ don't know

40. What is this a picture of? (See Figure 1)

2 - Marriage (getting married)/ wedding/ bride and groom

1 - man and woman together/ mention of church

0 - don't know

BODY PART IDENTIFICATION

55. Which is the woman and which is the man? Please label figure 2.

2 - man and woman identified correctly

1 - man or woman identified correctly

0 - don't know OR man and woman identified incorrectly

56. Which is the man and which is the woman? Please label figures 3&4.

2 - man and woman (back and front, identified correctly)

1 - identification of man and woman (back and front) in part correct

0 - don't know, or man and women identified incorrectly

On the Male

57. a) Label his eyes

b) What are they used for? What can you do with your eyes?

2 - correct label AND definition (to seek/ to look/ to watch)

1 - correct label OR definition (to seek to look to watch)

0 - incorrect label and definition OR don't know

58. a) Label his nose

b) What is it used for?

2 - correct label AND definition (to smell/ to breath)

1 - correct label OR definition (to smell/ to breath)

0 - incorrect label and definition (including to sneeze) OR don't know

59. a) Label his leg

b) What is it used for?

2 - correct label AND definition (to walks to stand on)

1 - correct label OR definition (to walks to stand on)

0 - incorrect label and definition OR don't know

60. a) Label his navel or his belly button

2 - correct label

0 - don't know OR incorrect label

61. a) Label his buttocks or his bottom

b) What is it used for?

2- correct label AND definition (to go to the toilet)

1 - correct label OR definition (to sit on)

0 - incorrect label and definition OR don't know

62. a) Label his feet

b) What are they used for

2 - correct label AND definition (to stand/ walk/ balance on)

1 - correct label OR definition (to stand on/ walk/ balance on)

0 - incorrect label and definition OR don't know

63. a) Label his penis

b) What is it used for?

2— correct label AND definition (answer must include 'for sexy sexual intercourse, or other term used to describe heterosexual or gay sex)

1 -correct label OR definition (any correct definition. going to toilet (weeing))

0 - incorrect label and definition OR don’t know

64. Label his chest

2 - correct label

0 - incorrect label OR don’t know

65. Label his ankles

2 - correct label

0 - incorrect label OR don’t know

On the female:

66. a) Label her arm

b) What is it used for?

2— correct label and definition (to move hand)

1 - correct label OR definition (to move hand)

0 - incorrect label and definition OR don’t know

67. Label her shoulder

2 - correct label

0 - incorrect label OR don’t know

68. a) Label her mouth.

b) What is it used for?

2 - correct label AND definition (talking / speaking/ eating/ kissing)

1 - correct label OR definition (talking / speaking/ eating/ kissing)

0 - incorrect label and definition OR don’t know

69. a) Label her breasts

b) What are they used for?

2 - correct label AND definition (breastfeeding/foreplay)

1 - correct label OR definition (breastfeed/ foreplay)

0 - incorrect label and definition (including bras as definition) OR don't know

70. a) Label her neck

b) What is it used for?

2 - correct label AND definition (to hold/ support or pivot/ move head)

1 - correct label OR definition

0 - incorrect label AND definition OR don't know

71. Label her hips

2 - correct label

0 - incorrect label OR don't know

72. a) Label her nipples

b) What are they used for?

2 - correct label AND definition (for babies to suckle)

1 - correct label OR definition (for babies to suckle)

0 - incorrect label AND definition OR don't know

73. a) Label her hands

b) What are they used for?

2 - correct label AND definition (to hold things/ to write/ draw)

1 - correct label OR definition (to hold things/ to write/ draw)

0 - incorrect label and definition (including definition of washing up or shopping) OR don't know

74. a) Label her vagina

b) What is it used for?

2 - correct label AND definition (answer must include; for sex/ sexual intercourse, or other term used to describe heterosexual or lesbian sex)

1 - correct label OR definition (for going to the toilet/ weeing/ for giving birth/ babies)

0— incorrect answer and definition OR don't know

75. Label her back

2 - correct label

0 - incorrect label OR definition

SEX AND SEX EDUCATION

81. What is meant by having sex?

2 - description of sexual acts/ penetration of vagina/anus/ sexual acts with partner

1- going to bed with someone, sexual intercourse/ being intimate with someone

0 - getting close/ having babies/ don't know/ getting together

MENSTRUATION

92. What is menstruation or periods?

2 - a woman's release of blood/ the lining of the womb/ a woman's menstrual cycle/ woman bleeding once per month to get rid of lining of womb/ bleeding from the vagina

1 - blood coming out (description of losing blood)

0 - time of the month/ sanitary wear/ don't know

95. Why does a woman have a period?

2- to discharge the lining of the womb (which has formed for the fertilisation eggs to attach to)

1 - because she has not fertilised the eggs (become pregnant)

0 - because it's the time of month/ don't know

96. How often does a woman have a period?

2 - every 28 days/ once a month

1 - about every 2 months/ a few times a year/ about every 3 weeks

0 - don't know/ frequently/ any other incorrect answer

97. Do men have periods?

Yes – 0 points

No – 2 points

101. FEMALES ONLY What do you do when you get your period?

2 - displays knowledge of using sanitary wear

1 - use those things (not explicit knowledge)

0 - get paid/ don't know/ nothing

102. FEMALES ONLY Do you know when your period is due or not?

2 - yes

1 - sometimes

0 - no

103. FEMALES ONLY What would you do if your period didn't come? (For example, see or tell someone. Who?)

2 - tell doctors staff/ parent/ carer

1 - tell a friend

0 – nothing/ don't know

104. When a woman has her period does the blood come out of the same hole where the urine or wee comes out?

Yes - 0

No – 2

105. Figure 5. What are these?

2 - sanitary wear: stating both tampax / tampons AND sanitary towels/pads

1 – tampax/ tampon OR sanitary towels/pads/ used for period/ hygiene products

0— don’t know/ incorrect answers (any description that is incorrect, i.e. cereal packets, condoms, tapes)

106. What are they for?

2 - to collect a woman’s blood during a period

1 - period

0 - don’t know/ incorrect answer

107. Can you tell me how to use them?

2 - tampax- insert/ put into vagina; sanitary towels, put them in your knickers/ underwear (must have knowledge of how to use both)

1 - put them up there/ soak up blood/ displays knowledge of how to use only one of these

0 - don’t know/incorrect response

SEXUAL INTERACTION

110. Figure 6. What is this a picture of? What are they doing?

2 - hugging/ holding each other/ holding arms or hands/ embracing

1 - they’re close/ together

0 - don’t know/ other incorrect answer

114. Figure 7. What is this a picture of? What are they doing?

2 - embracing/hugging/ kissing OR foreplay

1 -holding

0 - don’t know/ intercourse

120. Figure 8. What is this a picture of? What are they doing?

2 - snogging/ kissing/ French kissing

1 - closeness/ getting off with each other

0 - incorrect answer/ don’t know

128. What is sexual intercourse?

2 - penetrative sex/ insertion of a man's penis into a woman's vagina/ insertion of a man's penis into the anus

1 - sex/ making love/ sexual please

0 - don't know/ doing it

129. Figure 9. What is this a picture of? What are they doing?

2 - sex/sexual intercourse

1- shagging/ man and woman together, naked

0- man and lady laying down/don't know/another incorrect answer

133. What does it mean to have an orgasm or to come?

2 - climax of sexual excitements/ to reach the peak of excitement (in sex)/ to climax and ejaculate (release fluid)/

1 - to be excited/ use of other expression referring to orgasm

0 - don't know/ incorrect response, i.e. release of blood

134. Can a man have an orgasm?

Yes - 2 points

No - 0 points

135. Can a woman have an orgasm?

Yes - 2 points

No - 0 points

136. What happens when a man has an orgasm?

2- he ejaculates/ he releases sperm or semen/ he comes with pleasure of excitement

1 - he gets excited/ he moans with excitement/ his penis is hard/ erect

0 - don't know/ he is happy/ incorrect response

137. What happens when a woman has an orgasm?

2 - she comes with excitement/ releases fluid

1 - she gets excited/ she moans with excitement

0 - she is happy/ don't know/ incorrect response

138. What is ejaculation?

2 - ejection of fluid from female or semen from male/ release of fluid at the height of sexual excitement

1 - when a man or woman comes/ sexual excitement

0 - don't know/ incorrect response

139. What is semen for?

2 - reproductive fluid that carries sperm in males/ used to fertilise the female egg and make women pregnant

1 - to go inside a woman to make babies

0 - don't know/ to come/ other incorrect response

140. How much semen does it take to get a girl/woman pregnant?

2 - 1 sperm/ a very tiny amount

1 - not much

0 - any other response/lots/ a great deal

Additional: What is oral sex?

2 - sexual stimulation of penis or vagina using the mouth/ tongue

1 - using the mouth

0 - don't know/ talking about sex/ talking sexy/ other incorrect response

Additional: What is foreplay?

2 - stimulation preceding sexual intercourse/ stimulation and touching (of body and genitals) before sexual intercourse

1 - touching each other

0 - don't know/ incorrect response/ response referring to theatrical plays

Additional: What is anal sex?

2 - sexual penetration of the anus/ penis entering the anal passage of a man or woman for sexual pleasure

1 -'sex up the bum'/ other expression referring to anal penetration

0 - don't know/ incorrect response

147. Where do you do any of these things? (Have sexual intercourse/ orgasm)

2 – bedroom/ bathroom/ private place

1 - lounge

0 - TV room/ anywhere/ I don't know

148. Where do other people do these things?

2 - any response

0 - don't know/ they don't

149. Where is it OK to do these things?

2 - bedroom/ bathroom/ private place (lounge etc. if privacy mentioned)

0 - don't know/ they shouldn't/ in a public place

150. What do you do if someone wants to kiss you or have sexual contact with you and you don't want to?

2 - tell them 'no'/ tell them you don't want to

1 - say 'no', but apologise for this or give in/ ask them to wait/ put them off

0 - so yes OK even though you don't want to

151. What do you do if someone does kiss you or have sexual contact with you and you don't want them to?

2 - say 'no and push them away, report them to the policed parents/ carer

1 - tell someone/ tell them it was wrong

0 - let them do it and don't report it/ feel sorry for them/ get upset, but don't tell anyone/ don't know/ nothing

152. Can you say “no” to someone who wants to kiss you or have sexual contact with you?

Yes- 2 points

No- 0 points

153. How would you say “no”? Describe what you would do.

2 - ’no’ firmly/ I don’t want to (it’s my choice)/ shout at them (if necessary)

1- say ’no’ apologetically (as if with no right to)

0 - can’t say no/ don’t know

154. Who should decide about whether you have sex with someone or not?

2 - I should/ my partner AND I should (showing rights of personal choice)

0 - it’s up to my partner/ boyfriend/ girlfriend/ it’s up to the staff/ it’s up to my parents (showing that having sex is someone else’s choice and not the individual responding)

CONTRACEPTION

159. What is contraception or birth control?

2 - a means of preventing pregnancy

1 - condom/ the pills (name other contraceptive device)

0 - don’t know/incorrect answer

161. What is a condom?

2 - a contraceptive sheath/ a rubber sheath/ something a man puts on his penis to prevent pregnancy or spread of STDs (display knowledge of appearance and function)

1 - put it on a man’s penis/ willy/ it’s rubber/ like a balloon/ stops pregnancy (i.e. appearance or function)

0 - incorrect response/ don’t know

162. Figure 10. What is this a picture of?

2 - a man putting a condom/ rubber sheath on

1 - a man’s penis with a ’thingy’ on (to stop babies OR indicates knowledge of purpose of a condom)

0 - a penis/ other description of male genitals, not mentioning the condom/ a man holding his penis/ a man masturbating/ don't know Or other incorrect response

163. What is a condom for? What does it do?

2 - to help prevent/stop pregnancy AND spread of STDs (must mention both)

1 - to prevent pregnancy OR spread of STDs (need to mention 1 only)/ for safe sex/ a form of protection for sex/ a contraceptive device that protects you

0 - goes on a man's penis/ don't know/ other incorrect response/ makes sex better/ worse

164. Describe how you put on a condom.

2 - take out of packet and squeeze the end to release air, stretch and roll down on erect penis (descriptive account of how to put a condom on)

1 - put it on the penis/ willy (no description of how)

0 - don't know/ incorrect response/ unravel it

168. If you wanted to get a condom what would you do?

2 – family planning clinic/ chemist/ supermarket/ public house toilets/ doctors

1 - ask someone/go to doctor

0 - don't know/ buy one/ incorrect response

169. Can you name any other things you can use for birth control?

2 - pill/ cap/ coil/ femidom/ (names at least 2)

1 - names at least one of the above

0 - don't know/ incorrect response

170. Figure 11. What is this a picture of?

2 - the pill AND the cap/coil or condom (names both correctly)

1 - as above (names one correctly)

0 - incorrect response/ tablets/ tape measure/ don't know

171. What are they used for?

2 - to prevent pregnancy and/or control periods

1 - to protect you

0 - don't know/ incorrect response

PREGNANCY, ABORTION AND CHILDBIRTH

178. What is pregnancy? What does it mean to be pregnant?

2 - development of the child or the young in the womb/ when a female carries a child inside (the womb)/ fertilisation of the egg by the sperm to make a baby that the woman carries inside

1 - having a baby/ baby in the tummy/ going to have a child (refers to having a child without mentioning the womb)

0 – in there (points to tummy)/ don't known/ incorrect response

179. Figure 12. What is this a picture of?

2 - a pregnant woman/ a woman who is having a baby

1 - 'baby in tummy'

0 - don't know/ big tummy/stomach/ fat/ incorrect response

182. How does a woman get pregnant?

2 - sperm fertilises the egg after sexual intercourse/ through unprotected sexual intercourse

1 - sexual intercourse/ man puts his penis in the vagina/ sperm in the vagina

0 - don't know/ incorrect response

Additional Can women/girls get pregnant the first time that they have sex?

Yes- 2 points

No- 2 points

183. Can you have sex without the woman getting pregnant?

Yes - 2 points

No – 0 points

184. How do you stop the woman getting pregnant?

2 - use contraception/ use a condom/ the pill (other contraceptive device described)/ withdrawal method

1 – use protection

0 - don't know/ you can't/ incorrect response

185. Does the woman still get her period if she is pregnant?

Yes - 0 points

No - 2 points

(2 points for 'yes' if the respondent refers to 'spotting'/ or to the fact that occasionally women still bleed when pregnant)

186. Can a woman have a baby without getting pregnant?

Yes - 0 points

No – 2 points

2= also award 2 for 'if she adopts/ fostered (shows knowledge that she cannot have a child grow inside her without getting pregnant)

0= don't know

187. How long is a pregnancy? How long does the baby stay inside the mother?

2 - 9 months (term)/ 40 weeks

1 - full term/ between 6-12 months stated

0 - a long time/ incorrect response (any length of time less than 6 months or more than 12 months)/ don't know

188. How is a baby born?

2 - out of vagina or caesarean Section

1 - out 'down there'

0 - don't know/ incorrect response

189. Figure 13. What is this a picture of? What is happening?

2 - woman giving birth/ having a baby

1 - woman and baby (no mention of giving birth)

0 - don't know/ incorrect response/ having a smear test

192. Does the baby come out of the same hole as the blood when a woman has her period?

Yes - 2 points

No - 0 points

194. Can men get pregnant?

Yes - 0 points

No – 2 points

195. Do children under the age of 10 get pregnant?

Yes – 0 points

No – 2 points

197. What does a woman do if she gets pregnant and doesn't want the baby?

2 - has an abortion or termination

1 - gets rid of the baby/ gives the baby up for adoption

0 - don't know/ incorrect response

198. What is an abortion?

2 - natural or induced premature expulsion of the foetus/ a procedure to extract (get rid of) an unwanted foetus/ baby/ termination of pregnancy

1 - get rid of the baby/ 'kill' the 'child'/ foetus that's inside you (displays knowledge of extraction of foetus)/ destroy cells

0 - don't know/ incorrect response/ destroy eggs

SEXUALLY TRANSMITTED DISEASES

200. What is a sexually transmitted disease?

2 - a disease passed between partners during sexual contact (usually unprotected)

1 - AIDS (or the mention of another STD)/ a disease you catch during sex (no mention of unprotected)/ get it if a man doesn't wear a condom

0 - a bad thing/ don't know/ incorrect response/ germs/ an illness (no mention of nature)

202. How many types of sexually transmitted disease have you heard of? Please list them

2 – Herpes/ AIDS/ HIV/ Chlamydia/ Venereal disease/ gonorrhoea/ thrush/ syphilis/ crabs/ genital warts etc. (names at least two)

1 - As above (names at least 1)

0 - unable to name any STDs/'don't know/ incorrect response

204. How do you catch sexually transmitted diseases?

2 - through unprotected sexual contact sexual acts that exchange bodily fluids (blood/ semen)/ through having sex without using contraception

1 - through sex/ from someone else when you have sex

0 - don't know/ incorrect responses kissing/ through dirty people

205. How can you tell if you have a sexually transmitted disease?

2— through physical symptoms: sores/ warts/discharge/ pain in genitals/ not always visit doctor but can have a blood test

1 - in pain/ visit doctor

0 - don't know

206. Should you tell anyone if you think you have a sexually transmitted disease or not?

Yes- 2 points

No -1 point

207. Who should you tell?

2 - GP / doctor/ parent/ carer

1 - friend

0 - no one/ don't know/ you shouldn't

208. Should you have sexual intercourse if you think you have a sexually transmitted disease?

Yes- 0 points

No – 2 points

2 - for ‘yes’ with response: if you and your partner use contraceptive protection

0 - yes (if you like; no mention of contraception)/ don’t know

209. Why/why not?

As above

213. What is AIDS? What actually is it?

2 - Acquired immune deficiency syndromes a disease that attacks the immune system (progressive disease that comes from HIV)

1 - disease/ HIV/ STD/ a virus that kills/ describes symptoms

0 - don’t know/ germs/ something bad

214. What happens to you if you get AIDS?

2 - it attacks your immune system, and you get ill and may die/ immune system weakens

1 - you die/ you can’t have unprotected sex

0 - don’t know/ you get better/ take tablets/ incorrect response

217. What is the best way to stop getting AIDS?

2 - use contraceptive protection/ use a condom/ rubber sheath

1 - protect yourself (no mention of how)/ refers to not using needles

0 - don’t know/ you can’t/ other incorrect response

MASTURBATION

219. Figure 14. What are these pictures of? What are they doing?

2 – masturbating/ playing with themselves (sexually)/ sexually arousing themselves

1 - playing with self (no mention of sexual nature)/ touching breasts/ chest

0 - naked people looking for a breast lump/ don’t known incorrect response

220. What is masturbation?

2 - produce sexual arousal by manual stimulation of genitals/ touching oneself for sexual stimulation or arousal/ touching oneself for sexual excitements/ wanking/ giving pleasure to self/ fingering (other terminology used to refer to stimulation of genitals)

1 - touching self

0 - don't know/ incorrect answer

223. Figure 15. What are these pictures of? What are they doing?

2 - recognises both images as masturbating ('wanking')

1 - recognises one image as masturbating/ playing with him or herself/ fiddling with self

0 - don't know/ incorrect response/ laying on the bed

HOMOSEXUALITY (SAME SEX RELATIONSHIP)

235. What is homosexuality?

2 - same-sex relationships/ a sexual relationship between 2 men or 2 women/ a gay or lesbian relationship

1 - refers only to gay men having a sexual relationship OR only to two women having a sexual relationship

0 - don't know

Appendix 4

Sexuality Knowledge Scale For People with Intellectual Disability Sex- Ken- ID

MODEL ANSWER SHEET

Adapted from O'Callaghan and Murphy (2002)

This model answer sheet/ scoring manual has been adapted from the O'Callaghan and Murphy Sex-K- ID (2002), who adapted it from the original version of the SEX KEN-ID (McCabe; Fourth Edition, 1994). The adapted questionnaire uses all the knowledge-based questions extracted from the SEX KEN-ID scale. The changes to the model answer sheet made by me to improve the flexibility of the scoring and to clarify it, are highlighted. This model answer sheet only includes the scoring manual for the knowledge questions from the Sex-Ken ID questionnaire.

1. What is friendship?

2 points- enjoying company/ spending time with somebody/ trusting/ knowing the person well/ getting on/ sharing interests

1 point- friends/ mates/ going out/ people you have known long time

0 points- no answer/ Don't know/ an answer suggesting no awareness i.e. random word or statement

24. What is a date?

2 - attracted to a partner and going out with them (i.e. for a meal, to the cinema)/partners going out on a romantic date/ Specification of a place for date.

1 - romantic/ kissing, hugging, holding hands/ being asked out/ go out/ any other statement or word suggesting awareness

0- a date as in the day, month, year etc. / no answer/ don't know

31. What is meant by feeling close to someone? (please note that I suggested in the revised version of the SexKen that this question should not be included as some interviewees might find it difficult; however if using the original SexKen, the suggested model answer can be used)

2 - you like someone or trust, confide in/ feels nice to be with/ they're important

1 – physical closeness or examples of a behaviour suggesting closeness (physical i.e. hugging or emotional i.e. missing someone)

0 - no answer/ don't know

MARRIAGE

39. What is marriage?

2 - mention of vows + ceremony/ wedding + commitment to partner + ring (at least 2 of these mentioned)

1 - mention of commitment to partner for life OR wedding/ceremony OR buying of ring OR vows (1 of these mentioned)

0 - getting together/ no answer/ don't know

40. What is this a picture of? (See Figure 1)

2 - Marriage (getting married)/ wedding/ bride and groom

1 - man and woman together/ mention of church

0 - don't know

BODY PART IDENTIFICATION

55. Which is the woman and which is the man? Please label figure 2.

2 - man and woman identified correctly

1 - man or woman identified correctly

0 - don't know OR man and woman identified incorrectly

56. Which is the man and which is the woman? Please label figures 3&4.

2 - man and woman (back and front, identified correctly)

1 - identification of man and woman (back and front) in part correct

0 - don't know, or man and women identified incorrectly

On the Male

57. a) Label his eyes

b) What are they used for? What can you do with your eyes?

2 - correct label AND definition (to seek/ to look/ to watch)

1 - correct label OR definition (to seek to look to watch)

0 - incorrect label and definition OR don't know

58. a) Label his nose

b) What is it used for?

2 - correct label AND definition (to smell/ to breath)

1 - correct label OR definition (to smell/ to breath)

0 - incorrect label and definition (including to sneeze) OR don't know

59. a) Label his leg

b) What is it used for?

2 - correct label AND definition (to walks to stand on)

1 - correct label OR definition (to walks to stand on)

0 - incorrect label and definition OR don't know

60. a) Label his navel or his belly button

2 - correct label

0 - don't know OR incorrect label

61. a) Label his buttocks or his bottom

b) What is it used for?

2- correct label AND definition (to go to the toilet)

1 - correct label OR definition (to sit on)

0 - incorrect label and definition OR don't know

62. a) Label his feet

b) What are they used for

2 - correct label AND definition (to stand/ walk/ balance on)

1 - correct label OR definition (to stand on/ walk/ balance on)

0 - incorrect label and definition OR don't know

63. a) Label his penis

b) What is it used for?

2— correct label AND definition (to wee or any other words used to describe passing urine/ to have sexual intercourse/ any correct definition)

1 -correct label OR definition (any correct definition)

0 - incorrect label and definition OR don't know

64. Label his chest

2 - correct label

0 - incorrect label OR don't know

65. Label his ankles

2 - correct label

0 - incorrect label OR don't know

On the female:

66. a) Label her arm

b) What is it used for?

2— correct label and definition (to move hand)

1 - correct label OR definition (to move hand)

0 - incorrect label and definition OR don’t know

67. Label her shoulder

2 - correct label

0 - incorrect label OR don’t know

68. a) Label her mouth.

b) What is it used for?

2 - correct label AND definition (talking / speaking/ eating/ kissing)

1 - correct label OR definition (talking / speaking/ eating/ kissing)

0 - incorrect label and definition OR don’t know

69. a) Label her breasts

b) What are they used for?

2 - correct label AND definition (breastfeeding/foreplay)

1 - correct label OR definition (breastfeed/ foreplay)

0 - incorrect label and definition (including bras as definition) OR don’t know

70. a) Label her neck

b) What is it used for?

2 - correct label AND definition (to hold/ support or pivot/ move head)

1 - correct label OR definition

0 - incorrect label AND definition OR don’t know

71. Label her hips

2 - correct label

0 - incorrect label OR don’t know

72. a) Label her nipples

b) What are they used for?

2 - correct label AND definition (for babies to suckle)

1 - correct label OR definition (for babies to suckle)

0 - incorrect label AND definition OR don't know

73. a) Label her hands

b) What are they used for?

2 - correct label AND definition (to hold things/ to write/ draw)

1 - correct label OR definition (to hold things/ to write/ draw)

0 - incorrect label and definition (including definition of washing up or shopping) OR don't know

74. a) Label her vagina

b) What is it used for?

2 - correct label AND definition (for going to the toilet/ weeing/ for giving birth/ babies/ any correct definition)

1 - correct label OR definition (for going to the toilet/ weeing/ for giving birth/ babies)

0— incorrect answer and definition OR don't know

75. Label her back

2 - correct label

0 - incorrect label OR definition

SEX AND SEX EDUCATION

81. What is meant by having sex?

2 - description of sexual acts/ penetration of vagina/anus/ sexual acts with partner

1- going to bed with someone, sexual intercourse/ being intimate with someone

0 - getting close/ having babies/ don't know/ getting together

MENSTRUATION

92. What is menstruation or periods?

2 - a woman's release of blood/ the lining of the womb/ a woman's menstrual cycle/ woman bleeding once per month to get rid of lining of womb/ bleeding from the vagina

1 - blood coming out (description of losing blood, without mentioning where from)/ monthlies/ any other word used to describe menstruation

0 - time of the month/ sanitary wear/ don't know

95. Why does a woman have a period?

2- to discharge the lining of the womb (which has formed for the fertilisation eggs to attach to)

1 - because she has not fertilised the eggs (become pregnant)

0 - because it's the time of month/ don't know

96. How often does a woman have a period?

2 - every 28 days/ once a month

1 - about every 2 months/ a few times a year/ about every 3 weeks

0 - don't know/ frequently/ any other incorrect answer

97. Do men have periods?

Yes – 0 points

No – 2 points

101. FEMALES ONLY What do you do when you get your period?

2 - displays knowledge of using sanitary wear

1 - use those things (not explicit knowledge)

0 - get paid/ don't know/ nothing

102. FEMALES ONLY Do you know when your period is due or not?

2 - yes

1 - sometimes

0 - no

103. FEMALES ONLY What would you do if your period didn't come? (For example, see or tell someone. Who?)

2 - tell doctors staff/ parent/ carer

1 - tell a friend

0 – nothing/ don’t know

104. When a woman has her period does the blood come out of the same hole where the urine or wee comes out?

Yes - 0

No – 2

105. Figure 5. What are these?

2 - sanitary wear: stating both tampax / tampons AND sanitary towels/pads

1 – tampax/ tampon OR sanitary towels/pads/ used for period/ hygiene products

0— don’t know/ incorrect answers (any description that is incorrect, i.e. cereal packets, condoms, tapes)

106. What are they for?

2 - to collect a woman’s blood during a period

1 - period

0 - don’t know/ incorrect answer

107. Can you tell me how to use them?

2 - tampax- insert/ put into vagina; sanitary towels, put them in your knickers/ underwear (must have knowledge of how to use both)

1 - put them up there/ soak up blood/ displays knowledge of how to use only one of these

0 - don’t know/incorrect response

SEXUAL INTERACTION

110. Figure 6. What is this a picture of? What are they doing?

2 - hugging/ holding each other/ holding arms or hands/ embracing

1 - they’re close/ together

0 - don’t know/ other incorrect answer

114. Figure 7. What is this a picture of? What are they doing?

2 - embracing/hugging/ kissing OR foreplay

1 -holding

0 - don't know/ intercourse

120. Figure 8. What is this a picture of? What are they doing?

2 - snogging/ kissing/ French kissing

1 - closeness/ getting off with each other

0 - incorrect answer/ don't know

128. What is sexual intercourse?

2 - penetrative sex/ insertion of a man's penis into a woman's vagina/ insertion of a man's penis into the anus

1 - sex/ making love/ sexual please

0 - don't know/ doing it

129. Figure 9. What is this a picture of? What are they doing?

2 - sex/sexual intercourse/ any other word/ definition of sexual intercourse i.e. shagging, love making, going to bed with someone

1- man and woman together, naked

0- man and lady laying down/don't know/another incorrect answer

133. What does it mean to have an orgasm or to come?

2 - climax of sexual excitements/ to reach the peak of excitement (in sex)/ to climax and ejaculate (release fluid)/ use of other expression referring to orgasm i.e. to come

1 - to be excited

0 - don't know/ incorrect response, i.e. release of blood

134. Can a man have an orgasm?

Yes - 2 points

No - 0 points

135. Can a woman have an orgasm?

Yes - 2 points

No - 0 points

136. What happens when a man has an orgasm?

2- he ejaculates/ he releases sperm or semen/ he comes with pleasure of excitement

1 - he gets excited/ he moans with excitement/ his penis is hard/ erect

0 - don't know/ he is happy/ incorrect response

137. What happens when a woman has an orgasm?

2 - she comes with excitement/ releases fluid

1 - she gets excited/ she moans with excitement

0 - she is happy/ don't know/ incorrect response

138. What is ejaculation?

2 - ejection of fluid from female or semen from male/ release of fluid at the height of sexual excitement

1 - when a man or woman comes/ sexual excitement

0 - don't know/ incorrect response

139. What is semen for?

2 - reproductive fluid that carries sperm in males/ used to fertilise the female egg and make women pregnant

1 - to go inside a woman to make babies

0 - don't know/ to come/ other incorrect response

140. How much semen does it take to get a girl/woman pregnant?

2 - 1 sperm/ a very tiny amount

1 - not much

0 - any other response/lots/ a great deal

Additional: What is oral sex?

2 - sexual stimulation of penis or vagina using the mouth/ tongue

1 - using the mouth

0 - don't know/ talking about sex/ talking sexy/ other incorrect response

Additional: What is foreplay?

2 - stimulation preceding sexual intercourse/ stimulation and touching (of body and genitals) before sexual intercourse

1 - touching each other

0 - don't know/ incorrect response/ response referring to theatrical plays

Additional: What is anal sex?

2 - sexual penetration of the anus/ penis entering the anal passage of a man or woman for sexual pleasure

1 -'sex up the bum'/ other expression referring to anal penetration

0 - don't know/ incorrect response

147. Where do you do any of these things? (Have sexual intercourse/ orgasm)

2 – bedroom/ bathroom/ private place

1 - lounge

0 - TV room/ anywhere/ I don't know

148. Where do other people do these things?

2 - any response

0 - don't know/ they don't

149. Where is it OK to do these things?

2 - bedroom/ bathroom/ private place (lounge etc. if privacy mentioned)

0 - don't know/ they shouldn't/ in a public place

150. What do you do if someone wants to kiss you or have sexual contact with you and you don't want to?

2 - tell them 'no'/ tell them you don't want to

1 - say 'no', but apologise for this or give in/ ask them to wait/ put them off

0 - so yes OK even though you don't want to

151. What do you do if someone does kiss you or have sexual contact with you and you don't want them to?

2 - say 'no and push them away, report them to the policed parents/ carer

1 - tell someone/ tell them it was wrong

0 - let them do it and don't report it/ feel sorry for them/ get upset, but don't tell anyone/ don't know/ nothing

152. Can you say "no" to someone who wants to kiss you or have sexual contact with you?

Yes- 2 points

No- 0 points

153. How would you say "no"? Describe what you would do.

2 - 'no' firmly/ I don't want to (it's my choice)/ shout at them (if necessary)

1- say 'no' apologetically (as if with no right to)

0 - can't say no/ don't know

154. Who should decide about whether you have sex with someone or not?

2 - I should/ my partner AND I should (showing rights of personal choice)

0 - it's up to my partner/ boyfriend/ girlfriend/ it's up to the staff/ it's up to my parents (showing that having sex is someone else's choice and not the individual responding)

CONTRACEPTION

159. What is contraception or birth control?

2 - a means of preventing pregnancy

1 - condom/ the pills (name other contraceptive device)

0 - don't know/incorrect answer

161. What is a condom?

2 - a contraceptive sheath/ a rubber sheath/ something a man puts on his penis to prevent pregnancy or spread of STDs (display knowledge of appearance and function)

1 - put it on a man's penis/ willy/ it's rubber/ like a balloon/ stops pregnancy (i.e. appearance or function)

0 - incorrect response/ don't know

162. Figure 10. What is this a picture of?

2 - a man putting a condom/ rubber sheath on

1 - a man's penis with a 'thingy' on (to stop babies OR indicates knowledge of purpose of a condom)

0 - a penis/ other description of male genitals, not mentioning the condom/ a man holding his penis/ a man masturbating/ don't know Or other incorrect response

163. What is a condom for? What does it do?

2 - to help prevent/stop pregnancy AND spread of STDs (must mention both)

1 - to prevent pregnancy OR spread of STDs (need to mention 1 only)/ for safe sex/ a form of protection for sex/ a contraceptive device that protects you

0 - goes on a man's penis/ don't know/ other incorrect response/ makes sex better/ worse

164. Describe how you put on a condom.

2 - take out of packet and squeeze the end to release air, stretch and roll down on erect penis (descriptive account of how to put a condom on)

1 - put it on the penis/ willy (no description of how)

0 - don't know/ incorrect response/ unravel it

168. If you wanted to get a condom what would you do?

2 – family planning clinic/ chemist/ supermarket/ public house toilets/ doctors

1 - ask someone/go to doctor

0 - don't know/ buy one/ incorrect response

169. Can you name any other things you can use for birth control?

2 - pill/ cap/ coil/ femidom/ implant (names at least 2)

1 - names at least one of the above

0 - don't know/ incorrect response

170. Figure 11. What is this a picture of?

2 - the pill AND the cap/coil or condom (names both correctly)

1 - as above (names one correctly)

0 - incorrect response/ tablets/ tape measure/ don't know

171. What are they used for?

2 - to prevent pregnancy and/or control periods

1 - to protect you

0 - don't know/ incorrect response

PREGNANCY, ABORTION AND CHILDBIRTH

178. What is pregnancy? What does it mean to be pregnant?

2 - baby growing in the womb/ belly/ tummy; women expecting a baby

1 - 9 months/ big belly/ baby/ expecting/ any other word or description implying knowledge

0 – don't know/ incorrect answer

179. Figure 12. What is this a picture of?

2 - a pregnant woman/ a woman who is having a baby

1 - 'baby in tummy'

0 - don't know/ big tummy/stomach/ fat/ incorrect response

182. How does a woman get pregnant?

2 - sperm fertilises the egg after sexual intercourse/ through unprotected sexual intercourse

1 - sexual intercourse/ man puts his penis in the vagina/ sperm in the vagina

0 - don't know/ incorrect response

Additional Can women/girls get pregnant the first time that they have sex?

Yes- 2 points

No- 2 points

183. Can you have sex without the woman getting pregnant?

Yes - 2 points

No – 0 points

184. How do you stop the woman getting pregnant?

2 - use contraception/ use a condom/ the pill (other contraceptive device described)/ use protection

1 - not to have sex/ anal sex/ any other answer suggesting knowledge of not having vaginal sex with no protection/ withdrawal method

0 - don't know/ you can't/ incorrect response

185. Does the woman still get her period if she is pregnant?

Yes - 0 points

No - 2 points

(2 points for 'yes' if the respondent refers to 'spotting'/ or to the fact that occasionally women still bleed when pregnant)

186. Can a woman have a baby without getting pregnant?

Yes - 0 points

No – 2 points

2= also award 2 for 'if she adopts/ fostered (shows knowledge that she cannot have a child grow inside her without getting pregnant)

0= don't know

187. How long is a pregnancy? How long does the baby stay inside the mother?

2 - 9 months (term)/ 40 weeks

1 - full term/ between 6-12 months stated

0 - a long time/ incorrect response (any length of time less than 6 months or more than 12 months)/ don't know

188. How is a baby born?

2 - out of vagina or caesarean Section

1 - out 'down there'/ (out of) stomach/ belly/ tummy/ doctors cutting the tummy

0 - don't know/ incorrect response

189. Figure 13. What is this a picture of? What is happening?

2 - woman giving birth/ having a baby

1 - woman and baby (no mention of giving birth)

0 - don’t know/ incorrect response/ having a smear test

192. Does the baby come out of the same hole as the blood when a woman has her period?

Yes - 2 points

No - 0 points

194. Can men get pregnant?

Yes - 0 points

No – 2 points

195. Do children under the age of 10 get pregnant?

Yes – 0 points

No – 2 points

197. What does a woman do if she gets pregnant and doesn’t want the baby?

2 - has an abortion or termination/ gives the baby up for adoption

1 - gets rid of the baby (no specification how)

0 - don’t know/ incorrect response

198. What is an abortion?

2 - getting rid of/”killing” the baby/ termination of pregnancy

1 - miscarriage/ it’s what you do when you don’t want to have a baby

0 - don’t know/ incorrect response

SEXUALLY TRANSMITTED DISEASES

200. What is a sexually transmitted disease?

2 - a disease passed between partners during sexual contact (usually unprotected)

1 - AIDS (or the mention of another STD)/ a disease you catch during sex (no mention of unprotected)/ get it if a man doesn’t wear a condom

0 - a bad thing/ don’t know/ incorrect response/ germs/ an illness (no mention of nature)

202. How many types of sexually transmitted disease have you heard of? Please list them

2 – Herpes/ AIDS/ HIV/ Chlamydia/ Venereal disease/ gonorrhoea/ thrush/ syphilis/ crabs/ genital warts etc. (names at least two)

1 - As above (names at least 1)

0 - unable to name any STDs/'don't know/ incorrect response

204. How do you catch sexually transmitted diseases?

2 - through unprotected sexual contact sexual acts that exchange bodily fluids (blood/ semen)/ through having sex without using contraception

1 - through sex/ from someone else when you have sex

0 - don't know/ incorrect responses kissing/ through dirty people

205. How can you tell if you have a sexually transmitted disease?

2— through physical symptoms: sores/ warts/discharge/ pain in genitals/ not always visit doctor but can have a blood test

1 - in pain/ visit doctor

0 - don't know

206. Should you tell anyone if you think you have a sexually transmitted disease or not?

Yes- 2 points

No -1 point

207. Who should you tell?

2 - GP / doctor/ parent/ carer/ partners (current and ex)

1 - friend

0 - no one/ don't know/ you shouldn't

208. Should you have sexual intercourse if you think you have a sexually transmitted disease?

Yes- 0 points

No – 2 points

2 - for 'yes' with response: if you and your partner use contraceptive protection

0 - yes (if you like; no mention of contraception)/ don't know

209. Why/why not?

As above

213. What is AIDS? What actually is it?

2 - Acquired immune deficiency syndromes a disease that attacks the immune system (progressive disease that comes from HIV)

1 - disease/ HIV/ STD/ a virus that kills/ describes symptoms

0 - don't know/ germs/ something bad

214. What happens to you if you get AIDS?

2 - it attacks your immune system, and you get ill and may die/ immune system weakens

1 - you die/ you can't have unprotected sex

0 - don't know/ you get better/ take tablets/ incorrect response

217. What is the best way to stop getting AIDS?

2 - use contraceptive protection/ use a condom/ rubber sheath

1 - protect yourself (no mention of how)/ refers to not using needles

0 - don't know/ you can't/ other incorrect response

MASTURBATION

219. Figure 14. What are these pictures of? What are they doing?

2 – masturbating/ playing with themselves (sexually)/ sexually arousing themselves

1 - playing with self (no mention of sexual nature)/ touching breasts/ chest

0 - naked people looking for a breast lump/ don't known incorrect response

220. What is masturbation?

2 - produce sexual arousal by manual stimulation of genitals/ touching oneself for sexual stimulation or arousal/ touching oneself for sexual excitements/ wanking/ giving pleasure to self/ fingering (other terminology used to refer to stimulation of genitals)

1 - touching self

0 - don't know/ incorrect answer

223. Figure 15. What are these pictures of? What are they doing?

2 - recognises both images as masturbating (’wanking’)

1 - recognises one image as masturbating/ playing with him or herself/ fiddling with self

0 - don’t know/ incorrect response/ laying on the bed

HOMOSEXUALITY (SAME SEX RELATIONSHIP)

235. What is homosexuality?

2 - same-sex relationships/ a sexual relationship between 2 men or 2 women/ a gay or lesbian relationship

1 - refers only to gay men having a sexual relationship OR only to two women having a sexual relationship

0 - don’t know

Appendix 5

The Perceived Level of Knowledge- survey for parents (Study 2)

1. When shown a picture of a couple getting married, do you think your child would know what the picture was about?
2. When shown a picture of a dressed woman and a man, would your child know which one a woman and a man is?
3. When shown a picture of an undressed woman and a man, would your child know which one a woman and a man is?
4. Does your child know which sex has a penis?
5. Does your child know what the penis is used for (sexual function)?
6. Does your child know which sex has a breast?
7. Does your child know that the breast is used for feeding a baby?
8. Does your child know which sex has a vagina?
9. Does your child know that the vagina is used for conception and menstruation?
10. Does your child know that the vagina is used for birth?
11. Does your child know what is meant by having sex (heterosexual, vaginal)?
12. Does your child know what a menstruation or period is?
13. Does your child know why a woman has a period?
14. Does your child know how often a woman has a period?
15. If shown a picture of sanitary towels and tampons, would your child know what these were?
16. When shown a picture of a couple hugging, would your child know what the picture was about?
17. When shown a picture of undressed people kissing would your child know what the people in the picture were doing?
18. When shown a picture of people of opposite sexes having sex would your child know what the people in the picture were doing?
19. When shown a picture of people of the same sex having sex would your child know what the people in the picture were doing?
20. Does your child know what oral sex is?
21. Does your child know what anal sex is?
22. Does your child know what masturbation is?
23. Does your child know what petting or foreplay is?
24. Does your child know what having an orgasm means?
25. Does your child know what happens when a man has an orgasm?
26. Does your child know what happens when a woman has an orgasm?
27. Does your child know what ejaculation is?
28. Does your child know what semen is for?
29. Does your child know where it is OK to have sexual contact (understands public/private)?
30. Would your child know what to do if someone wanted to kiss them or have sexual contact with them but they didn't want to?
31. Does your child know what to do if someone DID kiss them or have sexual contact with them but they didn't want to?
32. Does your child think that they can say "no" to someone who wants to kiss them or have sexual contact with them?
33. Does your child know what a contraception or birth control is?
34. Does your child know what a condom is?
35. Does your child know how a condom is put on?

36. Does your child know where to get condom?
37. Does your child know what pregnancy is?
38. When shown a picture of pregnant woman, would your child know what the picture was about?
39. Does your child know how a woman becomes pregnant?
40. Does your child know how to prevent a woman from becoming pregnant?
41. Does your child think that a woman still gets her period when she is pregnant?
42. Does your child know how long a pregnancy lasts for?
43. Does your child know how a baby is born?
44. When shown a picture of a woman giving birth, would your child know what the picture was about?
45. Does your child think that a baby comes out of the same hole as the blood when a woman has her period?
46. Does your child know what an abortion is?
47. Does your child know what an adoption is?
48.Does your child know what a sexually transmitted disease is?
49.Does your child know how sexually transmitted diseases are contracted?
50. Would your child know if they had a sexually transmitted disease?
51. Would your child know that s/he should tell anyone if s/he thought s/he had a sexually transmitted disease?
52. Would your child know s/he should not have sexual intercourse if s/he thought s/he had a sexually transmitted disease?
53. Does your child know what HIV infection is?
54. Does your child know what happens to someone who develops AIDS?
55. Does your child know how to reduce the chance of getting HIV?
56. Does your child know what masturbation is?
57. When shown a picture of a man masturbating would your child know what the picture was about?
58. When shown a picture of a woman masturbating would your child know what the picture was about?
59. Does your child know what homosexuality is?
60. How many devices, that can be used for birth control, can your child name (such as a diaphragm, cap, implant, patch, intrauterine system or coil, contraceptive injection, vaginal ring)?

Appendix 6

The Big Five Inventory (John, Donahue, & Kentle, 1991)

Here are a number of characteristics that may or may not apply to you. For example, do you agree that you are someone who likes to spend time with others? Please tick a box next to each statement to indicate the extent to which you agree or disagree with that statement.

I am someone who…

Is talkative
Tends to find fault with others
Does a thorough job
Is depressed, blue
Is original, comes up with new ideas
Is reserved
Is helpful and unselfish with others
Can be somewhat careless
Is relaxed, handles stress well.
Is curious about many different things
Is full of energy
Starts quarrels with others
Is a reliable worker
Can be tense
Is ingenious, a deep thinker
Generates a lot of enthusiasm
Has a forgiving nature
Tends to be disorganized
Worries a lot
Has an active imagination
Tends to be quiet
Is generally trusting
Tends to be lazy
Is emotionally stable, not easily upset
Is inventive
Has an assertive personality
Can be cold and aloof
Perseveres until the task is finished
Can be moody
Values artistic, aesthetic experiences
Is sometimes shy, inhibited
Is considerate and kind to almost everyone
Does things efficiently
Remains calm in tense situations
Prefers work that is routine
Is outgoing, sociable
Is sometimes rude to others
Makes plans and follows through with them
Gets nervous easily
Likes to reflect, play with ideas

Has few artistic interests
Likes to cooperate with others
Is easily distracted
Is sophisticated in art, music, or literature

Appendix 7

Perceived Stress Scale (Cohen, Kamarck, & Mermelstein, 1983)

The questions in this scale ask you about your feelings and thoughts during the last month. In each case, you will be asked to indicate your response by ticking the box representing HOW OFTEN you felt or thought a certain way. Although some of the questions are similar, there are differences between them and you should treat each one as a separate question. The best approach is to answer fairly quickly. That is, don't try to count up the number of times you felt a particular way, but rather indicate the alternative that seems like a reasonable estimate.

1. In the last month, how often have you been upset because of something that happened unexpectedly?
2. In the last month, how often have you felt that you were unable to control the important things in your life?
3. In the last month, how often have you felt nervous and "stressed"?
4. In the last month, how often have you dealt successfully with day to day problems and annoyances?
5. In the last month, how often have you felt that you were effectively coping with important changes that were occurring in your life?
6. In the last month, how often have you felt confident about your ability to handle your personal problems?
7. In the last month, how often have you felt that things were going your way?
8. In the last month, how often have you found that you could not cope with all the things that you had to do?
9. In the last month, how often have you been able to control irritations in your life?
10. In the last month, how often have you felt that you were on top of things?
11. In the last month, how often have you been angered because of things that happened that were outside of your control?
12. In the last month, how often have you found yourself thinking about things that you have to accomplish?
13. In the last month, how often have you been able to control the way you spend your time?
14. In the last month, how often have you felt difficulties were piling up so high that you could not overcome them?

Appendix 8

Locus of Control scale (Rotter, 1966)

I am going to ask you some questions about the way you see the world.

You may agree with both statements but for each question please select the one that you agree with the most.

Children get into trouble because their parents punish them too much.
The trouble with most children nowadays is that their parents are too easy with them.

Many of the unhappy things in people's lives are partly due to bad luck.
People's misfortunes result from the mistakes they make.

One of the major reasons why we have wars is because people don't take enough interest in politics.
There will always be wars, no matter how hard people try to prevent them.

In the long run people get the respect they deserve in this world.
Unfortunately, an individual's worth often passes unrecognized no matter how hard he tries.

The idea that teachers are unfair to students is nonsense.
Most students don't realize the extent to which their grades are influenced by accidental happenings.

Without the right breaks one cannot be an effective leader.
Capable people who fail to become leaders have not taken advantage of their opportunities.

No matter how hard you try some people just don't like you.
People who can't get others to like them don't understand how to get along with others.

Heredity plays the major role in determining one's personality.
It is peoples' experiences in life which determine what they're like.

I have often found that what is going to happen will happen.
Trusting to fate has never turned out as well for me as making a decision to take a definite course of action.

Becoming a success is a matter of hard work, luck has little or nothing to do with it.
Getting a good job depends mainly on being in the right place at the right time.

The average citizen can have an influence in government decisions.
This world is run by the few people in power, and there is not much the little guy can do about it.

When I make plans, I am almost certain that I can make them work.
It is not always wise to plan too far ahead because many things turn out to- be a matter of good or bad fortune anyway.

There are certain people who are just no good.
There is some good in everybody.

In my case getting what I want has little or nothing to do with luck.
Many times we might just as well decide what to do by flipping a coin.

Who gets to be the boss often depends on who was lucky enough to be in the right place first.
Getting people to do the right thing depends upon ability. Luck has little or nothing to do with it.

As far as world affairs are concerned, most of us are the victims of forces we can neither understand, nor control.
By taking an active part in political and social affairs the people can control world events.

Most people don't realize the extent to which their lives are controlled by accidental happenings.
There really is no such thing as "luck."

One should always be willing to admit mistakes.
It is usually best to cover up one's mistakes.

It is hard to know whether or not a person really likes you.
How many friends you have depends upon how nice a person you are.

In the long run the bad things that happen to us are balanced by the good things.
Most misfortunes are the result of lack of ability, ignorance, laziness, or all three.

With enough effort we can wipe out political corruption.
It is difficult for people to have much control over the things politicians do in office.

A good leader expects people to decide for themselves what they should do.
A good leader makes it clear to everybody what their jobs are.

Many times I feel that I have little influence over the things that happen to me.
It is impossible for me to believe that chance or luck plays an important role in my life.

People are lonely because they don't try to be friendly.
There's not much use in trying too hard to please people, if they like you, they like you.

What happens to me is my own doing.
Sometimes I feel that I don't have enough control over the direction my life is taking.

Most of the time I can't understand why politicians behave the way they do.
In the long run the people are responsible for bad government on a national as well as on a local level.

Appendix 9

Participant Information Sheet (Study 2)

Thank you for taking interest in my research. Please find below detailed information about your participation and my research.

Sexuality is an important part of everyone's lives, but we do not know very much about relationships and knowledge of people with learning difficulties. I would also like to know more about experiences of carers and teachers and which factors affect attitudes in this area. It is an important subject and many parents face challenges related to this aspect of life. That is why I would like to invite you to take part in my research.

If you agree to take part in my research, you will be asked to complete an on-line survey consisting of: questionnaire about what you think your child knows about relationships and sexual health; personality questionnaire; questions about your beliefs about the world and your levels of stress; some demographic questions such as age etc. Please note that some of the questions are of a fairly explicit sexual nature. It takes about 30-45 minutes to complete the survey. There are no significant risks. All data will be anonymous and confidential.

You need to have a child with learning disability and live in the UK to take part. Your child can be of any age, including adult children.

Everyone who completes the survey and leaves their email address will be entered into a prize draw for £50 M&S voucher. In addition, I hope that the research will contribute to better knowledge about people with learning disabilities and will help to design effective guidelines for parents and educators.

The results of the study will be used for the purpose of my PhD dissertation and publication in academic journals. Brief report of findings will be given to the Royal Mencap to use in future policies, procedures and guidelines. You will not be identified in any report or publication.

Your participation in this research is voluntary and you have the right to refuse participation or to withdraw from participation at any point without prejudice or other consequences by contacting the researcher.

I would greatly appreciate if you could contribute to my research.

If you have any questions, please do not hesitate to contact me.

Appendix 10

Interview schedule (Study 3)

LEARNING DISABILITY AND SEX EDUCATION
INTERVIEW QUESTIONS

1. Tell me a bit about the sex education work that you do for young people with learning disabilities?
a. How long have you been doing this for?
2. What has your experience been like?
3. Do you think providing sex education is important? Why?

4. When you give sex education sessions, what are some of the typical things you would talk about?
5. What do you find most difficult or uncomfortable to talk about?
6. Are there any things that you feel is best not to talk about? Why?
7. What are some of the difficulties or challenges around talking about sex?

8. How do participants react to/behave when taking part in your workshops/lessons?
9. Which areas do participants have best knowledge of?
10. Why do you think this is?
11. Which areas do they have least knowledge? Why?
12. What factors affect their levels of knowledge?
13. What do you think they need to know? What are the most important areas in your opinion?
14. What do they want to know about?
15. What do they not want to know about?

16. What hopes/needs do they have when it comes to relationships?
17. What experiences do they have?

18. How do parents generally feel about their children taking part in sex education sessions?

Appendix 11

Participant Information Sheet (Study 3)

PARTICIPANT INFORMATION SHEET

The Research Project

1. Title of project

Investigating the sexual knowledge and needs of young people with learning disabilities and their parents and teachers' views and concerns.

2. Purpose and value of study

Sexuality is an important part of everyone's lives. However, very little is known about sexual knowledge and needs of young people diagnosed with different types of learning disabilities and autism. In my research I would like to explore how much young people know about sex, including contraception and sexually transmitted diseases, as well as what their needs and hopes are when it comes to relationships. I am also interested in the views and concerns of parents of people with learning difficulties and sex education teachers about sexuality of people with learning disabilities.

3. Invitation to participate

I would greatly appreciate if you could contribute to my research. Participation is voluntary and you will be able to withdraw at any time.

I will conduct structured, tape recorded interview with you. The interview will take about 30 minutes and I will ask questions about your views, experiences and concerns regarding sexual health education of young people with learning disabilities.

Additionally, I will send out a short questionnaire to those teachers whose students took part in my study asking about any possible consequences of young people's participation in the research.

If you have any questions, please do not hesitate to contact me. My email address and telephone number can be found below.

4. Who is organising the research

This research is being organised by Magda Charko who is currently a PhD research student at the Department of Psychology at Anglia Ruskin University in Cambridge. The research is being supervised by Dr Mick Finlay and Dr Steven Stagg who are both experienced researchers in the field of disability.

5. What will happen to the results of the study

The result of the study will be used for the purpose of my PhD dissertation and publication in academic journals. You will not be identified in any report or publication.

6. Contact for further information

Magda Charko
Research Student
Email: magdalena.borawska-charko@student.anglia.ac.uk

Anglia Ruskin University
Department of Psychology
East Road, Cambridge, CB1 1PT
Tel: 074567 07915/ 0845 196 2846/ 01223 363271 (ext. 2846)

Supervisor:

Dr Mick Finlay, email: mick.finlay@anglia.ac.uk

Your Participation in the Research Project

1. Why you have been invited to take part?

To my knowledge, there is no research about sexual knowledge and needs of teenagers/young people with learning difficulties in UK. However, it is an important subject and many parents and teachers/educators face challenges related to this aspect of life. I would like to find out more about it and that is why I would like to invite you to take part in my research.

2. Whether you can withdraw at any time, and how?

Your participation in this research is entirely voluntary and you have the right to refuse participation or to withdraw from participation at any point without prejudice or other consequences by contacting the researcher via e-mail, post or telephone.

3. What will happen if you agree to take part?

If you agree to take part, I will arrange an interview, during which I will ask questions about views, experiences and concerns regarding delivery of sexual health education to students with learning disabilities.

4. Whether there are any risks involved (e.g. side effects from taking part) and if so what will be done to ensure your wellbeing/safety

There are no significant risks.

5. What will happen to any information/data/samples that are collected from you?

All data will be anonymous and confidential. General results will be reported in my dissertation, in academic journals, and in conference presentations. Brief report of findings will be given to Mencap to use in future policies, procedures and guidelines.

Tape recordings will be destroyed after transcribing.

6. Whether there are any benefits from taking part?

There will be no direct benefits in taking part. However, I hope that the research conducted by me will contribute to knowledge about people with learning disabilities and will help to design effective guidelines for parents and educators for sexual education aimed at people with learning difficulties.

7. How your participation in the project will be kept confidential?

Questionnaires and tape recordings will be kept in a locked cabinet. Any information kept on computer will be password protected so only I will be able to access it.

YOU WILL BE GIVEN A COPY OF THIS TO KEEP,
TOGETHER WITH A COPY OF YOUR CONSENT FORM

Appendix 12

Framework Analysis - Chart 1

Theme 1: The challenges and difficulties to teaching- Subthemes and supporting quotes

Subthemes	General difficulties	Black and white thinking	Awareness of background	Cognitive abilities	Heterogeneous groups	Homophobia	Emotions	Negative parental attitudes	Prioritising	Puberty and anxiety	Difficult topics
Teacher 1		*For most students on the autistic spectrum everything is white or black.*		*Some of them have some form of communication problems, with speech or range of things, poor memory.*	*They are all very different levels, so it is very hard to get the group sorted out, cause they all, sort of understand at different stages as well*			*I think because our school population is very mixed, I think, again, parental attitude is very mixed, so for it goes from one extreme to the other.*	*So it is the dialogue and depth, how far I should go with it.*		*(…) they don't want to know about this or they do want to know about it [relationships], but they think it's dirty or whatever.*
Teacher 2				*Getting around their levels of comprehension and taking in things and remembering.*	*Sometimes in a group you have can some that are very sharp and know a lot and others in the same group that are not taking in.*	*Most of them is accepting. But again, we have one or two who got it fixed in their head that this is black and white. They have learnt that man and woman, mum and dad, two men-no.*		*We do have 1 or 2 pupils, whose parents are very fundamentally religious and will withdraw them from lessons, so that's a difficult one.*	*I think we just need to give them the basics of everything.*	*(…) body changes as well. They all want to know what's going to happen to them and if they're ok (….) There's a lot of anxiety associated with that.*	
Teacher 3	*It's just the range of what you can have in the classroom.*	*Some of our young people, (…) take things at face value.*	*A lot of the topic that we're covering are incredibly sensitive, (…) we may also be touching on things that*	*Constantly trying to reinforce and revisit things is very important and sometimes it's quite hard to pick up*	*We've got girls in year 10, who are into Frozen and dressing up as princesses (...) While we have got another young people, who are in*	*I think it's gradually changing, but I think there are still some young people, who struggle with that, more from*	*You also get pupils, who think they know it all, but actually they know the factual side of things*	*It's a difficulty of people having children with special needs that they're forced confronting things that most*	*There is only so much that you can actually do.*		

			affected their home lives as well.	*whether they understood something or not.*	*quite serious relationships in school, so that is a really big challenge.*	*embarrassment about it.*	*and not the relationships.*	*parents don't have to ever consider for their children and so that what I would find the hardest.*			
Teacher 4	*Everything that you teach has to be properly thought through, looked at from every angle.*	*It's kind of being very, very black and white about everything. You've got to make sure that there is no grey area at all.*		*It's hard when you are working with people with such a low level of development and communication. Just to be able to get the message across.*						*We will always teach about puberty and how your body changes, because obviously our kids have difficulty coping with change and so when their body starts changing, (...), that can be frightening for them.*	*(...) they're not interested at all [in relationships], (...) they just don't want to know and it causes so much anxiety for them.*
Teacher 5			*You have got to be aware of the background, things that may have happen to the student. You have got to sometimes be incredibly sensitive about it and be aware that some issues may not be*					*I have known some parents over the years who are: "Oh no, I am not dealing with that". They want to keep their child in a kind of a pre-adolescent bubble and unfortunately, it does not work cause no matter what is going to*		*I think periods and hormonal side of things can be tough for a lot of girls, they struggle with that, handling the whole situation. Boys do not really*	

			comfortable with all the students.					*happen the hormones will kick in and they will become sexualised young people and it is going to happen.*		*understand what is happening.*	
Teacher 6	*(...) how to include those less able pupils and make it appropriate for the more able kids.*			*Those working at lower level, it is very difficult. Just because of their capacity to understand and awareness of the world around them, awareness of their body parts is difficult.*	*We have got some guys who are almost at mainstream level and those who are functioning at very early stage, you know, almost childhood, and how you get those people included as well is very difficult.*			*Some pupils' parents say: ' my child does not need that' cause they are still viewing their children as a 5 years old when actually 17 years old and there are spending loads of time trying to touch themselves inappropriately, but it would be just 'no, you can't'. Parents in denial.*			
Teacher 7	*A lot of them because of their immaturity are thinking: 'this is never going to happen to me'*		*I am aware that some of my children have huge problems, so we have to be sensitive to them.*	*Then you have got other pupils, who are so limited. You probably just working on personal space and safety and, even if they are 14, they are still not able to process much more.*		*The next class, actually the more able one, (...), there were several students who turned away 'I can't look at it [two men kissing], that is disguising!', so we do have all kinds of barriers to cross.*	*We have got children, who may be able to understand the mechanics of sexual intercourse, but they do not have a clue about the context of sexual intercourse.*		*To cover everything that you need to in sex education you would probably have to teach it every day throughout the year.*		*We handed them [contraceptives] round and some children found that overpowering, overly direct.*
Teacher 8	*Addressing the students' own,*	*If you understand things in a*	*If you're looking at things such as*		*We've got a very broad mix of students, diverse*	*I think some people find challenges*		*The difficulty is always reaching the*			

	actual disability.	*black and white way, unfortunately the world doesn't work like that, so it can be quite difficult.*	*family relationships you need to know before you start what the family relationships are for the students within your class, because you can... people can, you know, get upset very quickly, you know, you have to be sensitive.*		*group of students and they have different levels of understanding different areas*	*around talking about same sex relationships.*		*parents that need the most support. It's the parents who need the most support, they're least likely to come to the training.*			
Teacher 9	*Because we have to sign it, sometimes it's a challenge, getting it across with the right signs and the right supporting understanding.*		*Some of our young people do unfortunately have backgrounds meaning that they've had unfortunate experiences, which is quite difficult for them.*		*We have a range of abilities, a range of difficulties, all sorts of syndromes and pretty much just about everything, it's all there really.*						
Teacher 10	*They will come up with most random things to ask you. And some share too much information.*		*I had a girl, whose mother had serious mental health issues and she said: 'I have to deal with this on day to day basis, I really don't need to hear at school'.*		*The range of the abilities is massive within this group, some children are quite mainstream, while others are less able.*	*There is quite a lot of them saying: 'eww', [when discussing homosexuality] and some of them say: 'it's not right'*		*Some of the problems are parents' attitudes.*			*It's usually the contraception or when we get the condoms out, some of the boys get very embarrassed.*

Educator 1	*This is an area that it is still left alone.*		*When people realise they were being abused that was very difficult.*		*Peoples' knowledge varies.*	*What people I worked with found difficult was often around lesbian, gay, bisexual issues. The huge amount of homophobia that was adopted from maybe the parents, maybe other carers who worked with them.*		*There is always a lot of anxiety among parents. Anxiety that education would make people less safe, when education makes them safer.*			
Educator 2	*People who have the greatest learning needs are often taught by the most unprepared in the field.*		*Some of them had experiences that were abusive.*		*There groups (…) who are very knowledgeable (…) right through to groups who have no clue.*			*I came across parents who have said: 'I do not want her to know that she has got a vagina, I do not want her to know that she can put anything there, in case other people would start putting things up there'.*			*Most of them are actually horrified about, sort of, sexual intercourse.*
Educator 3	*Unless it is delivered in a way that is meaningful (…), it is going to go straight over their head.*				*Some people seem to lack any experience whatsoever and then others seem to be quite experienced.*						*We have a model of a penis and they practise putting a condom. Some people were absolutely horrified.*
Educator 4	*How do you make it practical.*							*It's more about the people around them and somehow getting them to realise that the risks are not as big as they think.*		*Especially with kids with autism, giving them some kind of warning about what*	

										is going to happen to their body.	
Educator 5	*You might get one guy, who thinks he knows it all, but of course he does not.*			*He just did not understand what we were on about.*	*Those with Down syndrome- all they ever want is to welcome, have fun and everybody is lovely. Or somebody, who is on the autistic spectrum, they would not even want somebody to touch them. So it is complete contrast.*			*On the whole they [parents] are a little bit "why does my child want to know about sex. They are never going to have a sex."*	*There is so much that we would love to talk about but we have slotted times.*		

Appendix 13

Framework Analysis - Chart 2

Theme 2: How to overcome the difficulties- Subthemes and supporting quotes

Subthemes	Tools and techniques	Adapting to individual	Role-plays	Sense of humour	Self-esteem	Working with parents	Repetition	Starting early	Need for knowledge	Other tips and advice
Teacher 1	*A lot of visual work. You learn a lot by seeing (….) with all the resources visual ones are the most beneficial. If we can find things on-line. And keeping things simple. You just give them simple words and phrases, which we do across the whole school.*						*There is a lot recapping over last lesson, what do you remember from last week.*	*We also run the SRE groups, which we are starting now from primary- just learning about their bodies, public-private, stranger-danger, this sort of things.*	*They just really want to know.*	
Teacher 2	*We have to use symbols and really break it down (…). The way we teach is through visual things*	*[education needs to] remain very flexible and responsive to what they need.*	*We would talk about things in scenarios as well and trying to get them understand other people's points of view.*				*The more you go over it, the more it does eventually… some of it stays.*	*The government guidelines were encouraging schools to start SRE as young as possible as a safeguarding measure to prevent children from being abused (…) So you start from the young age, even up to until they are in sixth form as their mental capacity still operates at a very early stage.*	*Most of our students are open, they want to learn.*	
Teacher 3		*I try very hard to adjust what we do to particular pupils and quite often we don't follow set programme every year*		*I think that having a good sense of humour and that sort of thing is really, really important.*		*We try to work with parents and carers (…) that they understand the, sort of, messages and skills that we're teaching, so that if their child needs that, they can*	*I think that constantly trying to reinforce and revisit things is very important. We have to re-visit things a lot.*			

						build on and refer back to what they've done at school.				
Teacher 4	*For a lot of them symbols or sign language are too advanced for them, so we will use a lot of gestures. But everything is made very visual and objects references also. (…) It's got to be much more practical kind of thing for them.*	*It has to be appropriate in terms of their age, in terms of their ability. (…) I think it's just about looking at the individual and seeing what's important to them.*				*With something like autism it's so routine led, that if we're doing it at school and it's being done at home as well, it's much more likely to work than if they're being given mixed messages. (…) And so we have to be working with parents in that way, it's really important.*	*We use a lot of repetition, we use a lot of visual aids and the language that we use is very consistent.*		*You then find on the other side, they're really receptive to it, because if it's something that they want and they don't understand how to do it, then they want to know everything about it. It can become a fixation for them, that they want more and more information, because this is their big thing. And they want to know that what they're doing it's ok. They want to know that they're not wrong or that they're not going to get in trouble, and they don't need to worry about things and they like to be prepared for what might happen.*	
Teacher 5	*Depends what the topic is, you can split them by gender, ability group sometimes and understanding and it depends what the actual, specific topic is. Good way to get them engaged is to do some drawings*	*You need to be led by what they are coming up with and what their concerns are.*								*You try really hard not to feel uncomfortable yourself when talking about these things, which is sometimes quite hard, but I think they can pick up the fact that you are not comfortable talking about it.*

	(…) and looking at cartoons, videos is a good way to get them think about something.									
Teacher 6						*Working with parents as well, so there are sending the same messages. (…) We always try to invite parents to look at the resources and talk about what is going on if they are not sure or uncomfortable.*				*I think the bottom line is that they have somebody to speak to.*
Teacher 7						*We do send a letter out at the start of every summer to say what we are going to teach. (…) we have parents' evenings; we do have a lot of contact.*	*We know that they are not going to take on board everything that we say, so we just have to keep on revisiting.*			*We often go round the table and we say what we find uplifting about life, because for them some of these things are extremely challenging.*
Teacher 8	*We've got resources that are quite well equipped for purpose with those things (…) I think we, because of the nature of our students, we address things in a quite straight forward way. We tackle things head on. (…). Whereas here we do have to, we use a lot of diagrams, like a lot of appropriate types of photographs, videos to try to support them the best way we can.*	*It's looking at the students that we've got here, what is the priority for that young person to learn about rather than teaching strictly to the curriculum, because we've got the freedom to not have to do that in such a rigid way as some school have to I guess.*	*Role plays are massively useful tool that we use.*		*I think that's the one area that we need to do a lot of work in school, because it's about self-image and about how you view yourself and it's really important to frame it in a way of saying what support (…) I may need because of my disability and how I can be as independent as possible really.*	*Letter does go out to parents explaining topic that will be covered and if there any objections there.*	*The information has to be repeated and it has to be applied to a practical setting as well and often there's blurred lines and things aren't that simple as you would like them to be, you know.*	*It's about making it coherent strategy right through the school, so obviously you are not talking about same sex relationships at nursery [laughs], but you're talking about, you know... before you can do any that, you have to have an awareness of your own body and we do have students in sixth form, who don't know their own gender, so why are you talking about*		*I said to them: 'if you have got any questions, any personal questions then I want you to write them down, what is it that you really don't know about, you're embarrassed to talk about and we will help you to write it down and we will...'. It has to be meaningful [what you teach], it has to have purpose. When it's kind of generic, you are wasting your time really.*

								same sex relationships if the person doesn't know their own gender.		
Teacher 9	*We have to be very, very visual with getting the information across and you have to be diverse. For our students, you may say one thing and they'll look at you: 'what on earth are you talking about,' but actually when you go around in three different ways, they get it, then they understand it. Then they will come back and say: 'yes I know, I understand it' so it's about being flexible and diversifying stuff.*	*I try to be very open with the students. If they come to classroom and they find a piece on the television, we can discuss it.*	*We role play things.*	*[activity] just to break the ice, we have a good laugh about it. Then they know it's ok to talk about these things.*		*We do send letter home (…) and they says exactly what the contents of the lesson will be.*	*Quite often you have to go back, repeat it and repeat it, because they don't understand it fully the first time, so it's barriers to learning really.*			*We do research within the local area where they could go to get that information, who could help them on a range on topic. I am pretty open about my family and my own experiences and that sort of puts on the level with them rather than me standing in front of the classroom and saying: 'right, this is what we do'. I like to give them real life examples.*
Teacher 10	*We can use words, we can describe things, we can say we know people, who… but it has to be brought onto sensory level, so they experience it totally, otherwise it flies through their ears and it's gone.*	*When there is an issue or there is something worrying them or something has come up, then we, I can change the lesson.*			*We talk a lot about me, we try to say nice things about each other (…). I am trying to show them that they are moving on and thinking differently.*		*We will visit it again and again in the future years.*			*I actually really believe in it [sex education]. It's important. who's somebody they can trust, who can support them and also the places they need to go for proper advice. Advice that's reliable, so we do work on websites and places you can go locally and they can find where their local clinics are.*
Educator 1		*A lot of it would depend on what people wanted.*				*Some parents are incredibly supportive.*				
Educator 2	*I think one of the important things in teaching people with disabilities is that you need a variety of tools and resources.*	*Different things work with different students at different times.*							*They are usually really interested in the material*	*The other thing that I think is pretty important is that sexuality education should be coming from a variety of people and no one should rely on information that is coming only from an outside expert. It has to*

										come from parents, it has to come from school, it has to come from a variety of sources.
Educator 3			*We do lots of role play around difficult situations, what could they say.*							
Educator 4	*Most time you use analogy.*		*There was a social event coming on and we went through the whole night.*			*Usually before I run session for young people, I invite parents, so they can see the material, see what I am going to be showing or talking about and afterwards having contact with families as well to see if there was anything that they weren't happy about.*				*I wouldn't talk about things that you cannot have.* *I think for me as an educator is to keep boundaries and not talk about my own experiences, because it can help, but it can also come back to bite you too, so I guess keeping boundaries.*
Educator 5				*We approach it in a fun way to make them relax so they can feel open. I think these ice breakers are really, really important. Make it fun.*		*One of the mothers said [after taking part in session]: "That was amazing. I did not know what you were doing. That is why I came in."*			*So that is why we get more people who are eighteen, no sixteen plus who come. Because they actually can consent themselves. They want to know.*	*It is really important (…) that the room is the right place. (…) I think it is really quite nice to actually come away from the school, so that relaxes them because they are not on school premises, so they are in new environment, so the environment is really, really important.* *We finish on a really high note. Because we always…, some parts we are talking about are not so high, especially about safeguarding.*

Appendix 14

Framework Analysis - Chart 3

Theme 3: Important areas- Subthemes and supporting quotes

Subthemes	Safeguarding	Internet safety	Knowing what is right and wrong	Making choices	Human rights	Positive attitudes towards LGBT	Developing social life and skills
Teacher 1	*Safeguarding is always going to be the first priority.*	*We had internet safety as well. That was quite a big thing we did. Because our student very rarely go out, most of them, a lot of them do sit on Facebook, play video games with live link. And we did have situations where somebody wants to meet up with somebody, so we really went into that.*	*It is important to channel their education, so they know exactly what is going on, that it is ok and obviously the rules that go with that, like J. said, what is ok, what is not ok, what is acceptable, not acceptable. So they do not get themselves into trouble, they do not get somebody else into trouble and they do not become victims of crime.*		*At the end of the day they are human being and they have a right to experience all of those pleasures in life that most human beings do. It is a natural thing and a lot of them are curious.*	*We have talked about sex same relationships and had no problem with that. There are students here that would be in the same sex relationships.*	
Teacher 2	*It is the safeguarding that is probably the most important thing.*	*(…) with emphasize on things such as people taking pictures of themselves and putting them on-line in any shape and form, and obviously emphasising that it is not right to put pictures of yourselves with no clothes on and again, back to the internet safety, when see a picture of naked person, you should tell somebody, that it is not right to see that. It is important to cover every aspect and not worry about it.*	*Hopefully with the education they get, they know the rules and keep themselves out of trouble.*		*(…) the knowledge that as young people they have the right to experience emotional love and relationships.*	*We teach them that as human beings this is acceptable in the society. We do not pick people out. It is ok to have the same sex relationships and they exist. Without going into too much details, we are not allowed to promote too much, but it is important. Everyone has got a right to relationship whether it is the same sex or not.*	
Teacher 3	*Because whatever the level of their learning difficulty*				*And the other thing is about their entitlement to having a*	*I will always try when we talk about your*	*(…) when they leave school, they go to college and then everything stops. If they*

	or disability, people are very vulnerable, so I think to be able to recognise what they are not happy with and to give them skills to do something about it.				*loving relationship and friendship as well on whatever level that is for them and I think that's quite a tricky one because that does involve parents and carers and their attitudes.*	*feelings changing during puberty just to naturally say: 'some people are attracted to people of the opposite sex and some people to the same sex'.*	*are not going to get into a workplace or whatever, so they then become very socially isolated, so we're looking at in a wider picture really, trying to encourage parents to bring their children into to town to meet up with their friends and that sort of things, so I think the work that we do around sex and relationships is a part of wider programme about keeping a social life going and that's just as important as everything else, particularly for their mental well-being.*
Teacher 4	*How to keep themselves safe. That's the biggest one, by all way.*	*So you have to be very aware of things such as what are the laws regarding, you know, if you can order a porn on the internet, which a lot of our kids would do, and actually they are very specific laws about what is ok and what's not ok. And I think that's a real short falling for a lot of teachers particularly.*	*As far as possible to teach them what's socially acceptable, because they are never going to have a complete grasp of that, but they need to know the real black and white lines of what is and isn't ok. I think those real fundamental things are personal safety. It's a crucial thing*	*They don't like choice. They like to know what is or what isn't going to happen and a lot of them can find the choice element quite daunting: 'you can do this if you want to, but you don't have to' is a bit much for a lot of ours. They just want to know what it is and what it isn't ok for them to do. They don't want to know that they have any control over it. They just want to know what it is. So yeah, those are the hardest bits for us, I guess. There's a big emphasis on 'can you choose, can you say yes or no, do you have preference'- that's a different one to choice, because with choice you're given an option and you say:' which one do you want' . Preference is when you spontaneously say: 'I like this, I don't like this'. And for a lot of our children feeling like they can say 'no' to something is hard.*	*Everybody has a right to express themselves sexually. That's a human right and just because they have additional needs, they shouldn't be restricted from doing that. (...) Our children, whilst they do have disability and they have autism, physiologically they are normal, in inverted commas, they are the same as everybody else, so they will still have the hormonal changes or have the feeling that typical people have and so if you don't teach them how to deal with that, they are going to deal with that in an inappropriate way.*	*It's nice, because you kind of feel that you work with this level of special needs and you wish that the whole world could be like this, because they walk around in this bubble of total tolerance, total acceptance, everything.*	*I would hope that in the future we would have moreover opportunities for social. I think the difficulty is that all of them start at 18 at the moment, but it would be nice if we could do more to kind of develop things for them younger, like social events and this kind of stuff, but it's time, it's resources and there is also parental involvement. (...) I mean we do have a lot of afternoon clubs and we're running befriending schemes, so our staff go to the houses at the weekends and they will take them out to do like social things, but that tends to be more on a one to one basis or just in pairs and then with that, they kind of go with their best friend from school, who is probably not somebody they're going to be in a relationship with, but I think it's a gap and I think that's something we need to do more, especially for the more severely autistic people.*
Teacher 5	*I mean I have students that are incredibly vulnerable (...) And the figures back up that they are at increased risk of being harmed that*	*A lot of them are on-line, which is incredible, whole issue itself, you have to keep them safe on-line, but they are picking a lot of*		*As the students get older, they obviously have a specific set of needs and issues that need addressing, but also, they need a normal*	*I think they also need to know that they have a right to have a relationship and I think they have a right to have partners, to have babies*		

	other students. Equipping them to say 'no' in some situation and to understand the situations they are getting into, and being proactive about it if they can, just strategies to deal with situations and understanding how their body works.	*stuff, but I do not know how much they are processing.*		*type of education in keeping safe, making positive choices for themselves and just being more independent, just having some control over their life really.*	*if they wanted to in the future, all of that. Sometimes over the years if that has ever been stressed to them. Whether, you know, significant carers brought the issues, but they have a right to have their feelings and relationships as everybody else would, that needs to be stressed to them.*		
Teacher 6	*Focus is about keeping safe, appropriate touch, who can touch them. So that focus is on pupils being vulnerable in the society. They need to be aware that people can take an advantage; focus is on protecting them from the abuse as best as we can. (...) it is all about giving them a knowledge about if somebody is taking advantage or behaving inappropriately towards them, they have a right to say 'no'".*		*It is educating them when it [to masturbate] is appropriate, where you can do it, where you cannot (...) And then looking at boyfriends, girlfriends, what is appropriate, inappropriate, who you can touch, who you cannot touch, you know, and permitting as well is a big thing.*		*So as the pupils grow up they have awareness of, you know, sex education, contraception, again keeping themselves safe, but also making sure that because they have got special needs they are not discriminated against it, but also to recognise that it is healthy for them to have relationships, because they are members of society, those who want to, should be able to.*		
Teacher 7	*Just how to stay safe. It virtually covers the whole of SRE. How to be able to say 'no' to somebody. How to know their own feeling are telling them: 'this is not right'. And then the mechanics of staying safe, the importance of personal hygiene, importance of contraception. In a way that is the most I hope to tell them.*						*Children with special needs, need a lot of support with their relationships. Very many of them do not have friendships, in a way that you or I would understand friendships. It is always difficult when a boy and a girl in school, often they are isolated at home, so school is their main social club, so it is only natural that they try to form their friendships and relationships here.*
Teacher 8		*I think, I think that the magazines and TV and the internet has been for a lot of people... it's their, has been their main source of information on sex*	*I think you should, it's very important that you teach about boundaries, rights, legal things. I think consent it's a huge issue and I think it*	*I think as a country we probably need a slightly more mature approach to it and looking how we can support young people making right choices and*	*I think it's about their rights actually. I think they're not always sure what they're allowed to do and what they aren't allowed to do. I think that's quite confusing*		*The students here, they can be very happy within their bubble at times, but they are within a bubble. They go to afternoon clubs, which are controlled here, you know, they are not going out to do what 16, 17 year old do: going to*

		education type things and actually, in my view, it's quite...it creates distorted view, particularly in terms of how they see women, I think.	*starts right from, right back from a very young age.*	*being as well equipped for going into relationships at different times of life as possible.*	*message for people with learning disabilities.* *I think that the most important thing is that as a teacher or educator that the young person with disability or without a disability has the right to sexual expression and to be able to have their own identity sexually in terms of... (...). I think what sometimes happens particularly with people with disabilities, it's decided by the people who work with them and because it's uncomfortable, that they are not, that they should be de-sexualised or they shouldn't have any sexual thing, because of their disability and because society finds it awkward and I think the main thing you should, your main, starting principle should be that the person is entitled to sexual identity in the way everyone else is in whatever way that's sort of manifest itself.*		*town and meeting people, they are not going to hang around the parks together generally and things like that, so it's all quite controlled sort of environment that they are in. (...) And also the reality is that a lot of people have got... who our students consider their friends, are people that are paid to be with them. And it doesn't mean that those people don't like them, but it's a different dynamic, you know, different dynamic. If you can get to 18, 19 years old and not have a true friend, that can happen. It's quite sad really and I think, you know, we try to support them to make as many friendships as we can.*
Teacher 9	*To be safe, to be really safe. It's about making sure that they are safe because at the end of the day, they're so many risks in lives and especially with my students. They're so vulnerable that they need to know how to be safe. There are too many opportunities for them not to be.*						
Teacher 10	*I want them to be safe, I want them to know what to do when things go right or wrong or whatever.*	*They are not getting that contact with their peers. They try to make contact via internet, Facebook and it always seems to lead to problems, because parents*		*I mean some of them cannot make a choice. You give them choice of 2 different drinks, and they cannot manage that.*	*If you are saying: 'no, no, no, we are not telling them about it' [loving relationship], they can become victims or we keep them away from everybody, so they can never*		*But it's so difficult, because they are more insulated from the real world, because they don't travel, well some of them travel independently now, but they go out and about lots, they don't see as many people of their own age, they don't*

		won't control it. We have got that problem with Facebook, with texting. Loads of stuff is being brought back to school because this is their only chance, the small pool that we have got here, it's their only chance of interacting with others and it's always... at the moment we are having real problems... and with the parents taking control of it.		*It's the grey areas that they're really have trouble and making choices I would say it's a real challenge for our children, even small things. And they want to please. They tend to, not all of them, but most, their default setting is to please you. If I said the sky was green, they would say 'yes'. So it's getting them to disagree with you, so sometimes I say: 'if I say this, what do you think?' and getting them to start to disagree, start them to think for themselves.*	*experience that, we are denying them a really important part of life. So I think it's so important. If they have got to learn about everything, why they shouldn't learn about that as well.*		*get out there in the world and they are sort of kept… their family, their computer it's their life, so you sort of have to push them out- what about this, what about that, because they don't experience the whole thing and they are likely to stay in that teenage frame of mind much longer, in that sort of bigoted, tunnel vison for a lot longer than possibly other kids who are going out, like going to college or university, where they have to mix with other people and they're suddenly: 'whoa, this is the real world'. Ours are more protected from it in a way.*
Educator 1	*About abuse and what to do if it does happen. And if they are unhappy with what happened to them, they need to know who they can talked to and what can happen.*		*People need to know their rights, they need to know the law.*		*People have a right to knowledge and a right to make decisions around their sexual lives, they are sexual being, including being parents themselves. And they are not told about law and their rights either. People are often told that they should not be parents- why not? Some people are told that they were not allowed to get married- again- why not? Who makes that law? Nobody I know of. So people need to know their rights, they need to know the law.*		
Educator 2	*I am pretty hot on safety issues (…) So we talk a lot about safety.*		*And it has been a problem of not recognising the boundaries too (…) Again, it was the lack of social inhibition that was the greatest problem.*		*I believe people have a right to education, whatever stage they are at, so I do not think that there is anything that needs to be held back because somebody has got a learning disability.*		
Educator 3	*Just because we are giving them the information, it does not necessarily mean that it is going to happen, but it is a possibility and*	*The younger groups tend to have better knowledge of staying safe. I am not saying they are staying safe on the internet, but*	*If they trust everybody, that obviously is going to be a huge problem and just appropriate*	*(…) to empower them really to be able to make their own decisions about what their do in their life. (…) Often with people with learning*	*To understand also that they have to right to be in a relationship. That they do not have to put up with horrible behaviour and relationships.*		

	they know how to behave and what to do to keep themselves safe if it does happen.	*they have more knowledge around the internet, how to meet people, but are not necessary putting precautions in place.*	*behaviour with other people.*	*disabilities, decisions are made for them. It is either somebody thinking that they know best or it is quicker, easier and life goes on in that way. But why should people do that, why should they not have the information and the confidence to say: 'actually I would like to do this' or 'I do not want to do that'. I think it is their right and I am quite passionate about that.*	*That they the right for it to be balanced and not taken for granted. That they know how to stay healthy in a relationship or relationships.*		
Educator 4	*Talking about language that is going to be useful to have to keep you safe, sometimes using the F word to a person, who you think might hurt you is a good skill to have.*				*I am probably more likely to talk to disabled people about how to be activist, they rights.* *I think I wish that people knew more about their own power, so it's not about the practical things or having sex or anything like this. I wished that more people lived more fully in their skin.*		
Educator 5	*Safeguarding, your own personal space is so, so important.*			*That is why we always say: "Everybody has got a choice. You have a choice to say yes or to say no. Think about it. Take some time to think about it and then make your mind up."*			*You always get one or two who probably be out and about, going to the pub. When others probably stay at home and watch television all the time and never venture out. So they have little knowledge of people and I think that is down to parents by sheltering them. They are teenagers; they should be out and about. Just because they have got a disability, why that should prevent them.*