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**SEX EDUCATION FOR PEOPLE WITH AUTISTIC SPECTRUM  
DISORDER AND LEARNING DISABILITIES**

Section A: A Systematised Review of Research Investigating the ‘Supports’  
which Facilitate Individuals with Autistic Spectrum Disorder to Develop  
Intimate Relationships.

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### **Summary of the Major Research Project**

**Section A** is a systematised review of empirical research exploring which ‘supports’ (e.g. other people, sex education) and sources of information facilitate individuals with autistic spectrum disorder (ASD) to develop intimate relationships. This review aimed to provide a more contemporary review of the research in this area, since the most recent review, in 2010. A systematic literature search revealed seventeen papers relating to the research questions. A synthesis and critique of the findings is presented. The clinical implications are highlighted, as well as a need for further research in this area, including on adaptations to sex education for individuals with ASD with covarying learning disabilities (ASD-LD).

**Section B** is an empirical study which investigated the perceptions of 21 health and social care professionals, experienced in delivering sex education for adults with ASD-LD.

Professionals’ views were gathered on the characteristics of adults with ASD-LD which need to be considered when delivering sex education, and the adaptations required to facilitate the delivery of sex education. Professionals completed three iterative rounds of questionnaires, using a Delphi method. Findings showed that professionals agreed that adults with ASD-LD have unique characteristics for which specific adaptations to sex education are required.

Clinical and research implications are presented.

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**Section A:  
A Systematised Review of Research Investigating the ‘Supports’ which Facilitate  
Individuals with Autistic Spectrum Disorder to Develop Intimate Relationships.**

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### **Abstract**

Individuals with Autistic Spectrum Disorder (ASD) have an expressed desire for intimate relationships, but they can be difficult to navigate for this population. As research about sexuality and ASD continue to develop, this paper offers a more contemporary review of the literature, to build upon the findings from a previous 2010 review. This systematised review explored which ‘supports’ (e.g. other people, sex education) and sources of information facilitate individuals with ASD to develop intimate relationships. A systematic literature search of various databases revealed 17 empirical papers, 14 assessed as good quality. The findings show that individuals with ASD access a variety of supports, including; parents, sex education programs, school, peers, partners, religion, and the internet, pornography and media. Parents and professionals have a role in delivering sex education to individuals with ASD. Sex education programmes can increase individuals with ASD’s knowledge. However, they report dissatisfaction with previous sex education. Peers may be an additional source of information. Partner accommodation of individuals ASD-related needs may facilitate the success of intimate relationships. The internet is a preferred source of information for individuals with ASD. However, it remains unclear which sources of support are most effective. The clinical and research implications are presented.

Key words: Autistic spectrum disorder, sex education, sexuality, intimate relationship, support

## **1. Introduction**

The introduction presents a definition of ASD and intimate relationships, then outlines the relevant literature on individuals with ASD, and their experiences of intimate relationships. Finally, a summary of a previous literature review (Gougeon, 2010) on the topic of ASD and sex education is presented, leading to the rationale and aims for the current review.

### **1.1. Autistic spectrum disorder (ASD)**

ASD is a neurodevelopmental disorder characterised by social communication difficulties, social interaction difficulties, rigid interests, repetitive stereotyped behaviours, sensory processing difficulties, and a concrete thinking style (American Psychiatric Association, APA, 2013). In the Diagnostic and Statistical Manual 5<sup>th</sup> edition (DSM-V; APA, 2013), ASD is an overarching disorder for; Asperger's disorder, autistic disorder, childhood disintegrative disorder, and pervasive developmental disorder-not otherwise specified (PDD-NOS). Although prevalence rates vary, a large proportion of individuals with ASD (approximately 50% to 70%) also have learning disabilities (LD; Baird et al., 2006; Fombonne, Quirke, & Hagen, 2009), which includes significant impairments in adaptive and intellectual functioning (intelligence quotient (IQ) below 70) present before 18 years old (APA, 2013).

### **1.2. Intimate relationships**

Intimate relationships are interpersonal relationships involving emotional and / or physical closeness. Unlike friendships, those in intimate relationships may express their emotions through romantic and sexual behaviours (La Greca & Harrison, 2005). Research has shown that being in an intimate relationship can increase an individual's level of social support and resilience against physical and mental health problems (Braithwaite, Delevi, & Fincham, 2010; La Greca & Harrison, 2005; Reis & Franks, 1994). Females have been found to prefer

developing intimate relationships through conversations, whereas males prefer to do activities together (McNelles & Connolly, 1999). Research suggests more committed intimate relationships lead to greater relationship and sexual satisfaction (Feeney & Collins, 2001; Sprecher, 2002), which are maintained when individuals have increased empathy (Davis & Alan, 1987), social skills (Segrin & Taylor, 2007), and communication skills (Burleson, Kunkel, Samter, & Working, 1996).

### **1.3. Individuals with ASD and intimate relationships**

Historically, individuals with ASD were falsely assumed to be disinterested in intimate relationships, which led to the sex education needs of this population being neglected (Konstantareas & Lunsky, 1997). Most individuals with ASD have expressed a desire to experience intimate relationships (Byers, Nichols, & Voyer, 2013; Strunz et al., 2017). However, individuals with ASD have less knowledge about sex and relationships than typically developing (TD) individuals, and are more likely to become socially isolated (Jobe & Williams White, 2007; Koller, 2000).

Intimate relationships involve a complex set of social rules, which makes navigating them difficult for people with ASD. This is thought to be associated with an impaired 'theory of mind' (Baron-Cohen, Leslie, & Frith, 1985), which makes empathising and understanding the perspective of others difficult. Difficulties with interpreting social and non-verbal cues (Bauminger, 2002), can impede the ability of individuals with ASD to recognise warning signs of abuse (Nichols & Blakeley-Smith, 2009) and implicitly learn social rules (Hudson, Nijboer, & Jellema, 2012).

Findings suggest that some individuals with ASD engage in more socially and sexually inappropriate behaviours, such as stalking, to seek intimate relationships (Stokes, Newton, & Kaur, 2007; Sullivan & Caterino, 2008). These behaviours can be misunderstood, perceived as deviant, and result in legal consequences (Sevlever, Roth, & Gillis, 2013; Stokes et al., 2007). The sensory sensitivities of individuals with ASD may make sexual contact aversive and anxiety provoking (Aston, 2012), leading to a reduction in sexual experiences (Byers, Nichols, & Voyer, 2013), whereas some others seek out sensory fulfilment through more unusual or dangerous sexual behaviours (Fernandes et al., 2016; Hellemans, Colson, Verbraeken, Vermeiren, & Deboutte, 2007). A preference for structure and routine may make adapting to partners' needs difficult for individuals with ASD (Ray, Marks, & Bray-Garretson, 2004).

Research suggests that mainstream sex education is not equipped to meet the needs of individuals with ASD, so they are often reliant on their family, healthcare and education professionals as sources of tailored sex education (Dewinter, Vermeiren, Vanwesenbeeck, & van Nieuwenhuizen, 2013; Konstantareas & Lunsky, 1997; Murphy & Elias, 2006). However, adapted sex education provision for this group remains poor and inconsistent, and is often provided as a reactive intervention for inappropriate behaviours (Gougeon, 2010; Sullivan & Caterino, 2008). Also, sex education research has focused more upon the needs of those with LD (Sullivan & Caterino, 2008). Overall, it appears that a combination of ASD-related characteristics and poor access to tailored sex education has reduced opportunities for individuals with ASD to successfully develop meaningful intimate relationships.

#### **1.4. Gougeon's (2010) review on ASD, sexuality and sex education**

The most recent review of the literature, associated with individuals with ASD, their sexuality and sex education, was conducted by Gougeon (2010). As there was a paucity of research in this area, Gougeon conducted a broad but thorough critical review of 13 studies published between 1990 (when 'autistic disorder' became an official disorder in the DSM-III-R; APA, 1987) and 2010. A comprehensive literature search was conducted using broad search terms, and a criterion which determined the exclusion of studies focusing on individuals with LD or developmental disabilities, as these groups' needs may differ from those with ASD. A clear summary table of the main findings was presented, and the research was critically appraised, allowing the reader to consider the findings' quality.

Three key themes arose from the review's findings. Firstly, individuals with ASD were found to be interested in developing intimate relationships, dispelling societal preconceptions that they are uninterested in sex and relationships. Secondly, the sexual behaviours of individuals with ASD were often perceived as problematic, including gender identity issues, unusual sexual interests, and socially inappropriate behaviours. Parents were found to be concerned that these behaviours would be misinterpreted by others, but parents did not know how to best communicate with their children about sex education. Finally, individuals with ASD found it difficult to apply taught information on sex and relationships to real-life. Overall, the main sources of sex education for individuals with ASD were their parents, and they were less likely to learn from their peers, compared to TD individuals.

The importance of Gougeon's review is that it highlights a need to better adapt sex education provision to the unique needs of individuals with ASD, and that society (e.g. negative



attitudes, problematising views of ‘ASD-sexuality’) can act as a barrier to sex education for this population, and ultimately the development of desired meaningful relationships.

### **1.5. Rationale and scope of the current literature review**

Since 2010, research and ideas about sexuality and ASD have rapidly developed. Therefore, a more contemporary review of the research is required, to reflect current knowledge and values, and to be more applicable to clinical practice. Research has focused more on the role of others (e.g. parents) and sex education interventions to improve opportunities for individuals with ASD to develop intimate relationships. Thus, the current review aimed to synthesise and critically appraise empirical research, published after 2010, which focused on the role of ‘supports’ (see section 1.5.1. for definitions) and sources of information which facilitate individuals with ASD to develop intimate relationships. This review may elicit recommendations, and prompt further research aimed at improving existing supports and provisions of sex education for this population. A systematised review was conducted as it allows for a systematic literature search, synthesis and quality assessment of research findings (Grant & Booth, 2009).

#### **1.5.1. Terminology**

‘Supports’ are defined as external supports which individuals with ASD access to enhance their knowledge and skills to develop intimate relationships, including other people, sex education programmes, and other sources of information (e.g. media, internet, etc.). Also, ‘sex education’ is defined as the informal communication about, or formal teaching of, topics relating to sexuality, sex, and relationships.

### **1.5.2. Aim and research questions**

This systematised review aimed to synthesise and appraise the empirical literature since 2010, on the ‘supports’ and sources of information which facilitate the development of intimate relationships for individuals with ASD.

1. What ‘supports’ facilitate individuals with ASD to develop intimate relationships?
2. From what sources do individuals with ASD gain their sexuality knowledge and skills to develop intimate relationships?

## **2. Method**

### **2.1. Literature search**

A systematic search of four electronic databases (PsycINFO, Applied Social Science Index and Abstracts, and Web of Science) was conducted (Figure 1). The terminology to describe ASD and intimate relationships have been used interchangeably across the literature, and ‘support’ is an ambiguous term. Therefore, broad search terms were used in the literature search, including ‘autism’, ‘autistic spectrum disorder’, ‘autistic’ or ‘Asperger’s’, combined with ‘intimate relationship’, ‘romantic relationship’, ‘sexual relationship’, or ‘sexuality’. The final search was conducted in February 2017. The initial search revealed 367 articles. After a review of the titles, 272 abstracts were screened against the inclusion criteria (see below). Then, 35 full-text articles were assessed for eligibility, and their reference lists were checked to ensure all relevant studies were included. Overall, 17 studies met the criteria and were included in this review.

### **2.2. Inclusion criteria**

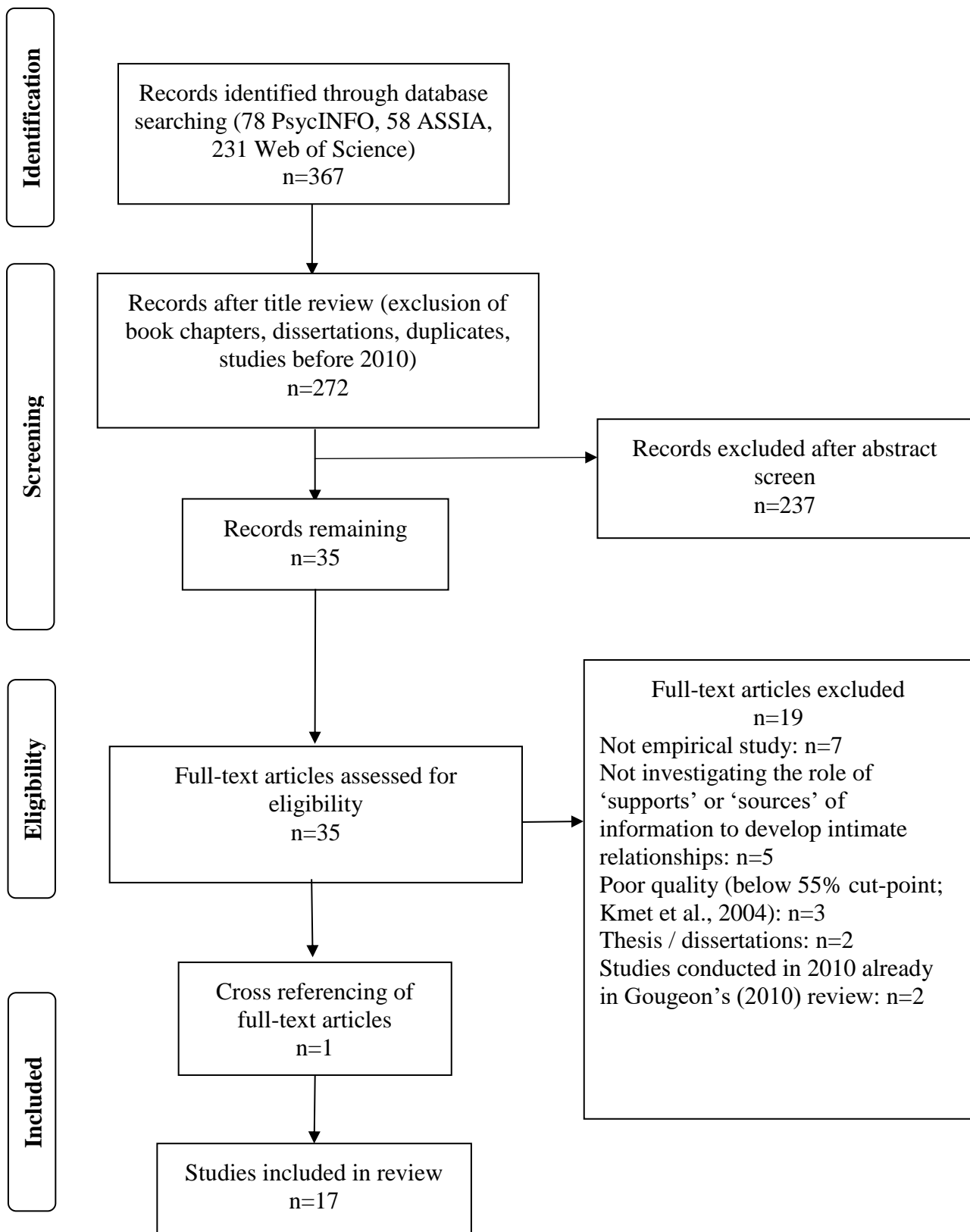
- Empirical studies from peer-reviewed journals.
- Studies in English

- Published from 2010 onwards, since Gougeon's (2010) review (see section 1.4.).
- Investigated the role or impact of external 'supports' or sources of information (see section 1.5.1.) on the knowledge and skills required for individuals with ASD to develop intimate relationships.
- Participants had ASD, or were individuals who provided 'supports' for individuals with ASD.

### **2.3. Exclusion criteria**

- Not specifically referring to those with ASD (e.g. 'developmental disabilities'), to ensure the 'supports' relate to the unique needs of individuals with ASD.
- Studies which used the term 'sex education' to refer to sex and relationships 'knowledge', but made no reference to the role of sex education as a supportive intervention.
- Studies exploring other types of interpersonal relationships e.g. friendships.
- Theoretical papers or dissertations.
- Papers assessed as poor quality, and below the lowest cut-point (below 55%) as measured by Kmet, Lee, and Cook's (2004) quality criteria (see section 3.4.), as they would limit the accuracy of the findings.

Figure 1: Flow-diagram of systematic literature search details



## **2.4. Quality assessment**

The quality assessment tool by Kmet et al. (2004) was used to assess the quality of the reviewed studies, as it is applicable to a variety of study designs. It encompasses two systematic scoring systems (Appendix A), through which quantitative and qualitative studies are scored based on specified standards. Papers which score above the highest cut-point (<75%) are considered good quality, and those scoring below this cut-point are considered as poorer quality. The lowest cut-point is 55%, suggesting poor quality.

## **2.5. Search results**

Seventeen studies met the criteria and were included in this review. There were ten quantitative, five qualitative, and two studies mixed-methods studies, one of which primarily used quantitative measures.

## **2.6. Structure of review**

A summary and critique of the 17 studies is presented based upon the findings' main themes associated with the 'supports' and 'sources' of information which facilitate individuals with ASD to develop intimate relationships. These included<sup>1</sup>; parents (n=10), sex education interventions (n=10), healthcare professionals (n=4), school-based sex education (n=7), peers (n=6), partners (n=4), religion (n=2), and the internet, pornography and media (n=6). Lastly, a discussion of the findings and the clinical and research implications is presented.

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<sup>1</sup> Frequencies higher than number of studies, as studies reported on more than one support/source.

### **3. A systematised review of empirical studies**

#### **3.1. Key findings**

The 17 studies' key findings are summarised in Table 1. Fourteen studies were rated as good quality (>75%), one of which scored poorer in quality for its qualitative element (Roth & Gillis, 2015). Three studies scored slightly below the 75% cut-point (Tables 2 and 3).

Table 1: Summary of reviewed studies

Study	Aims	Design	Sample	Measures	Analysis	Key findings
Dewinter, Parys, Vermeiren & Nieuwenhuizen (2017), Netherlands	To explore how adolescent boys with high-functioning ASD experience their sexuality and sexual development.	Qualitative	8 male adolescents, 16-20 years old, autistic disorder/Asperger's disorder (measured by author in previous study on Autism Diagnostic Observation Schedule; ADOS; Lord et al., 2000), below average IQ or higher (>70).	Interviews; Meaning of sexuality. Topics were love, relationships, body changes, masturbation, experiences of partnered sex, sex education, and pornography.	Interpretative phenomenological analysis (IPA). Three main themes: 1. 'Developing sexual self', 2. 'Interpreting sexuality-related information in my surroundings', 3. 'Exploring relationships and partnered sex'.	1. Difficulties understanding their ASD-related difficulties. 2. Parents/ caregivers talking about sexuality limited. Peers talking about sexuality encouraged to explore sexuality. Internet/ pornography accessible source of information for majority. All received sex education in school, 7/8 satisfied with it. 3. 7/8 interested in partnered sex. 5/8 experienced partnered sex (most positive experience). Adapting to <i>partners'</i> routines and preferences difficult, but most successfully had.
Corona, Fox, Christodulu & Worlock (2016), USA	Evaluate the feasibility and outcomes of a pilot sexuality and relationships education program for adolescents with ASD and their parents (see Table 4 for intervention description).	Pre-post, experimental feasibility intervention study.	1 parent per adolescent (6 mothers, 2 fathers). 8 adolescents with ASD (2 females, 6 males), 12-16 years, PDD-NOS (n=4), Asperger's syndrome (n=3), autism (n=1). Education: part mainstream/special (n=6), mainstream (n=1), home-schooling (n=1). Criteria: verbal communication, can participate in group, severe conduct problems excluded.	Parent measures: - Sexual Behaviour Scale (SBS; Stokes & Kaur, 2005); adolescent behaviour and knowledge. - 3 questions from Intimate/Romantic subscale in Courting Behaviour Scale (CBS; Stokes, Newton, & Kaur, 2007). - Parent concern (authors; 4-point Likert scale). - Parent Questionnaire (authors); number of, and comfort with, sex education topics discussed with children. - Parent Satisfaction Questionnaire (PSQ; authors); program feasibility (10 items, 5-point Likert scales). Adolescent measure: Adolescent Knowledge Questionnaire (authors); 10-items on topics covered.	SBS: qualitative analysis (unspecified), descriptive statistics.  Comfort Likert scales: descriptive statistics.  Adolescent knowledge, number of topics parents discussed, parent comfort: t tests. PSQ – descriptive / indicator of program utility.	Behaviour/knowledge of adolescents: 75% adolescents desired romantic relationship, 50% pursued romantic relationship, 75% unsure how to develop intimate relationships. Sex Education: 87.5% of adolescents previously received sex education. 87.5% understood puberty, 71% of understood reproduction. Parent Concerns: 75% parents concerned children would be taken advantage of. Significantly reduction in parental concern. Adolescent Knowledge Questionnaire: no significant difference in adolescent knowledge. Parent Questionnaire: parents discussed significantly more topics with adolescents. No significant differences in parent comfort. PSQ: 75% satisfied with program.
Cunningham, Sperry, Brady, Peluso &	Exploration of the effects of group-treatment	Pre-Post experimental	38 adults with ASD (30 males, 8 females), 18 to 50+	<u>Self-report measures:</u> Social skills: Social Responsiveness Scale 2 (SRS-2; Constantino &	Preliminary analyses:	No differences between treatment groups pre-treatment on outcome measures. No effects of treatment conditions.

Pauletti (2016), United States of America (USA)	programme: comparing Relationships Enhancement® (RE) and adapted version for people with ASD (RE-ASD; see Table 4 for descriptions), on social skills, empathy and social support.	Participants randomised to one of two treatment conditions (RE or RE-ASD)	years, average verbal communication skills, 10 <sup>th</sup> grade reading level, most minimum education was high school. Married (n=3), single (n=35). Majority Caucasian (n = 25).	Gruber, 2012), Autism Quotient (AQ; Baron-Cohen, Wheelwright, Skinner, Martin, & Clubley, 2001). Social skills (dating and assertion): Dating Assertion Questionnaire (DAQ; Levenson & Gottman, 1978). Empathy: Empathy Quotient (EQ (Baron-Cohen & Wheelwright, 2004) Social support: Social Provisions Scale (SPS; Cutrona & Russell, 1987).	- Independent samples t test (treatment group differences) - Mann-Whitney U test (male/female disparity). Mixed-design ANOVA (11 analyses): effects of treatment condition, time, etc.	Pre- to post-test: - Overall significant improvements in empathy and social skills, but not social support. - Significant reductions in SRS-2, and three subscales (social communication, social motivation, restricted interests and repetitive behaviours), significant increases in DAQ dating domain, significant increases in EQ. - No effect of time on SRS-2 subscales (social awareness and social cognition), the AQ, DAQ (assertion domain), or SPS.
Hannah & Stagg (2016), United Kingdom, (UK)	Explored young adults with ASD's feelings about sex education and their sexual awareness	Mixed-methods: Between-subjects design and qualitative interviews.	40 adults (18-25 years old): - 20 ASD (12 males, 8 females), no self-reported LD, authors did not assess IQ. - 20 typically developing individuals (TD; 7 males, 13 females). - 4 with ASD, and 4 TD individuals took part in qualitative interviews.	Sexual knowledge, experience, feelings and needs scale (SexKen; McCabe, 1999): 1 subscale (Sex Education); feelings /needs for sex education. Sexual awareness questionnaire (SAQ, Snell, Fisher, & Miller, 1991); 36-items, 5-point Likert scales, 'sexual-consciousness', 'sexual-monitoring', 'sexual assertiveness', 'sex appeal consciousness'. Semi-structured interview; 10 questions, follow-up questions, 15 minutes. Sources of sex education. Perceptions of sex, relationships and sex education.	Quantitative; independent sample t tests.  Qualitative; thematic analysis. Themes: dissatisfaction with school sex education, sexuality, social difficulties, negative experiences, understanding others.	Quantitative results: - ASD group did not think they needed more sex education. - ASD group had significantly lower scores on sexual awareness than TD group. - No significant difference between ASD and TD groups on sex education feelings /needs.  Qualitative results: ASD group lacked knowledge and confidence on sex and sexuality compared to TD group. Peers are a source of sex education for TD group. ASD group had less peer interaction.
Holmes, Himle, & Strassberg (2016a), USA.	Relationship between symptoms of ASD, parental romantic expectations (PRE), and parent provision	Quantitative survey design, cross-sectional.	190 parents (most Caucasian and female, mean 47.06 years old). 190 adolescents with ASD (12-18 years old; 165 males, 25 females).	Online sexuality survey: 50-items. - Parent and child demographics - PRE of child; 5-point Likert-scale, likelihood of child to experience; sexual desires, dates, love, sexual relationships, marriage/ life partner, have children. - Parent-child sexuality communication; parents select	Descriptive statistics and multiple and simple linear regression analyses. - Conducted for whole sample, and then separately for ASD + average or	Whole sample: - ASD severity did not predict NSTC - Parents of adolescents with more severe ASD had lower PRE. - Greater PRE significantly predicted higher NSTC. - Child age / gender not predict PRE/ NSTC. - PRE mediated relationship between ASD severity and NSTC.



	of sex education.		Asperger's syndrome (n=84), autism (n=60), PDD (n=90), more than one diagnosis (n=26). IQ levels (parent-reported): average/above-average IQ (86–116; 68.9%), below average/ borderline IQ (71 – 85; 12.6%), below average IQ (mild LD; 56–70; 8.4%), moderate LD/ far below average IQ (41–55; 4.7%), severe/ profound LD (IQ<40, 5.2%).	'number of sexuality-related topics' (NSTC) covered with their child. 39 topics from previous research findings: privacy, sexual abuse, physical development, reproduction, pregnancy, sexually transmitted infections (STIs), sexual decision-making, relationships, consent, coercion, sexual health. Social Responsiveness Scale second edition (SRS-2; Constantino & Gruber, 2012): Parent reported, 65-item rating scales. Severity of ASD symptoms, focused on social impairment (Awareness, Cognition, Communication, Motivation, Repetitive Behaviour).	above IQ and ASD + below average IQ. - Gender and age controlled for.	ASD+ parent-reported average or above IQ: - Lower PRE for children more severe ASD symptoms - Child age / gender not predict PRE/ NSTC. - PRE mediated relationship between ASD severity and NSTC. - More impaired social awareness, restricted interests and repetitive behaviour significantly predicted lower PRE, but social cognition, social communication, and social motivation did not. ASD+ parent-reported average or below IQ: - More severe ASD the lower PRE - PRE score did not predict NSTC - More impaired social motivation, social communication, social awareness, and restricted interests and repetitive behaviour significantly predicted lower PRE.
Holmes, Himle & Strassberg (2016b), USA.	Investigate the relationship between ASD symptoms, parental sexuality - related concerns, and parent-child sexuality communication.	Quantitative survey design, cross-sectional.	131 parents (mostly Caucasian and female; median age 46 years old). 131 adolescents (12-18 years old), gender not reported, IQ levels (parent-reported): 52.7% average IQ (86-115), 47.3% above average IQ (116+). - SRS-2 (ASD severity); most scores in line with ASD diagnosis. 3.8% below diagnosis threshold (included based on parent-	Online sexuality survey: 50-item. - Parent and child demographics - Parent-child sexuality communication (PCSC). - Parental sexuality-related concerns - Parent self-efficacy in PCSC and readiness to manage child's sexual development and behaviour (5-point Likert-scale). - Parent belief likelihood sexuality education lead to inappropriate sexual behaviour (5-point Likert-scale). Social Responsiveness Scale second edition (SRS-2): Parent reported, 65-items, severity of ASD symptoms. Parental Sexuality Concern Inventory (PSCI): level of concern about 21 sexual behaviours and	Preliminary analyses of data conducted in Holmes and Himle (2014). PSCI: principal component analysis, t tests. Normally distributed variables; Pearson's correlations or simple/ multiple linear regressions. Non-normal distributions; Spearman rank-order correlations and negative	Previous analyses (Holmes & Himle, 2014): - NSTC ranged 0–39 (average of 21.95). - PSCI ranged 0-84 (average 34.74). Parental concerns and child characteristics; - Social Communication on the SRS-2 predicted PSCI. - ASD severity predicted parent expectations and concerns about negative outcomes, relationships, and practical concerns, but not parent concerns about sexual deviance. - Greater parent concerns for children with more severe ASD. Parental concerns and PCSC: - PSCI did not predict NSTC. - Parental belief that sex education would lead to inappropriate sexual behaviour did not predict NSTC. - Parent readiness to manage child's sexual development and behaviour correlated with

			reported previous ASD diagnosis).	relationships outcomes/ issues (5-point Likert-scales). Parental sexuality education inventory (PSEI): 39 sex education topics. Number of sexuality topics parents discuss with child (NSTC).	binomial regressions.	'practical concerns and expectations' and 'concerns about sexual deviance' on PSCI. - Parent self-efficacy correlated with 'practical concerns and expectations' on PSCI. Parental readiness and self-efficacy predicted NSTC.
Mackin, Loew, Gonzalez, Tykol, & Christensen (2016), USA	1. Explore parents' perceptions of the sex education needs of their children with ASD. 2. Explore parents preferred methods of delivering tailored educational intervention strategies.	Descriptive qualitative research design	15 parents (1 male, 14 females; 35-60 years old, most Caucasian, n=12) of adolescents and young adults with ASD (4 male, 2 females, 14-20 years). Parent-reported ASD diagnosis: autism (n=5) PDD-NOS (n=9), Asperger's syndrome (n=2).	Focus groups (n=5 parents) and telephone interviews (n=10 parents): - structured interview guide pilot tested and developed by an experienced panel in ASD; researchers, clinical staff, parents, and an adolescent with ASD.	Summative content analysis. 7 themes: 1) Ability to engage in relationships, 2) Role responsibility, 3) Child's history of sexual education, 4) Fears and concerns, 5) Content preferences, 6) Facilitators and barriers to sexual education, 7) Recommendations for development of intervention.	1) n=2 parents believed child would experience intimate relationships. n=2 of children with lower ability believed this would prevent sexual relationships. 2) Most believed sex education was their role (n=10), healthcare provider's role (n = 9; primary care, paediatricians, psychiatrists, psychologists), and school's role (n = 9) Few believed other family members, church and peers should provide sex education. 3) All children experienced sex education (formal/informal), n=10 in school. Most parents (n=14) provided sex education. Other sources of sex education: media (e.g. television, Internet), peers, community programs, healthcare providers, and church. Sex education adaptations; verbal, conversations, formal instruction, visuals. 4) Lack of information/ resources, exploitation/abuse, child's poor social understanding, child interpreting porn as reality, dating, consent, sexting, stigma. 5)'Matters of maturation', 'consequences of sexual behaviour', 'social navigation'. 6) Facilitators; accurate/ASD-specific information/resources, child interest, parent support. Barriers; child disinterest, child/ parent embarrassment/ fear getting it wrong. 7) Visuals, interactive, ASD-specific, technology, repetition, accessibly written information, contextual information, evaluation, parent feedback, at child's pace, modelling, child

						values, group format, affordable, applicable to school, brief, include parents.
Dekker et al. (2015), The Netherlands	Pilot study of whether the Tackling Teenage Training (TTT) can increase psychosexual knowledge (see Table 4 for intervention description).	Pre-post training design	30 adolescents and young adults with ASD (11-19 years old; 23 males, 7 females. PDD-NOS (n=24), Asperger's syndrome (n=3), autistic disorder (n=3) assessed with ADOS. IQ<75 assessed with various measures. Referred for psychosexual issues/ prevention.	Psychosexual knowledge test: 37 items (35 multiple-choice, 2 open-ended questions), adapted from Dutch school biology sexual knowledge test for adolescents (e.g. sexual language, function of sex, safety, and knowledge applied to context). ADOS: Module 4 to assess ASD severity. Trainer-rated adolescent motivation, resistance and difficulty: scale 0-10. Parent-rated adolescent knowledge applied to daily life: 'yes' or 'no'.	Descriptive analyses: diagnostic characteristics, trainer- and parent-ratings, correct answers on psychosexual knowledge test. Repeated-measures ANOVA to analyse whether increases in knowledge was significant.	- Psychosexual knowledge significantly increased between pre-(M= 25.80, SD= 6.30) and post-training (M= 33.80, SD = 2.72; F (1, 29) = 65.20, p< .001); particularly sexual selfhood and behaviour. - Younger adolescents showed a significantly greater increase in psychosexual knowledge. - Adolescents with greater trainer-rated difficulty showed significantly greater increase in psychosexual knowledge. - Parents reported perceived transfer of knowledge to daily life.
Ginevra, Nota & Stokes (2015), Italy.	To investigate parent perceptions of sexuality in adolescents with ASD and Down's syndrome (Ds), compared with TD adolescents.	Cross-sectional survey design	269 parents (mean age 47.43 years) of TD adolescents (n=94; 65 females, 29 male), of Ds adolescents (n=93; 60 females, 33 male), and of ASD adolescents (n=82; 25 females, 57 male) 269 adolescents (11-18 years old) TD (50 male 44 female), Ds (41 male, 52 female), ASD (63 male, 19 female). No IQ data	Sexual Behaviour Scale (SBS; Stokes & Kaur, 2005): Translated into Italian. Parent reports of their child's; Social behaviour (7-items), Privacy awareness (17-items), Sex education (17-items, e.g. knowledge about sexuality-related issues, sources of sex education), Sexual behaviour (11-items). - Parental concerns about child (4-items, e.g. others misinterpretations of child's behaviour, child misunderstandings about sex/relationships).	Preliminary analyses. Pearson's correlations between subscales. MANOVA for differences TD, Ds, and ASD groups. Variance and normality checks. Exploratory cross-sectional analysis of developmental patterns (e.g. age).	- ASD group have poorer social behaviour and less sex education compared to Ds and TD group (did not report sources of sex education). - Parents had greater concerns for ASD and Ds group, and they displayed less appropriate sexual behaviour than TD group. - With increased age: sex education improved for TD group, decreased for Ds group, and not improve ASD group. ASD groups knowledge of privacy increased and parent concern improved. Sexual behaviour did not change with age. - Parents of ASD group concerned others would misinterpret children's sexual behaviour.
Barnett & Maticka-Tyndale (2015), Canada.	Exploration of the sexual identities and sex education	Qualitative	24 adults self-identified ASD (18-61 years old. Gender identity: 13 feminine,	Semi-structured, Internet-facilitated interview and 21 demographic questions: Interview format chosen by participants (e.g. email, chat,	Descriptive analyses of demographics.	1) High gender variance. First intimate experiences later than general population (n=15 after age 18, n=5 after age 30). 2) difficulties interpreting social cues, etc.

	experiences of adults with ASD.		6 masculine, 5 genderqueer, 1 androgynous. 21/24 completed post-secondary/professional education (as evidence for above-average IQ). - 16/24 in intimate relationship.	Skype audio streaming). 18 email interviews (1-12 months; mean 3 months). 2 chat interviews, 4 audio streaming interviews (chat and audio 4-4.5 hours, two sittings). - How participants describe their sexuality and sexual experiences, and how this is influenced by service supports (Topics included; e.g. support services and sex education).	Semantic-level thematic analysis of interview data. Themes: 1) Distinctive features of sexuality, 2) Courtship (dating) concerns, 3) Sensory dysregulation, 4) Sex education, 5) Shared Strategies for Success.	3) sexual sensations as aversive, etc. 4) Previous sex education inadequate and not appropriate for those with disabilities (e.g. sensory difficulties). Taught reproduction at school, but overall school sex education limited. Preferred topics: non-heterosexuality, sexual/sensory needs, dating, recognising positive/abusive relationships. Parent provision of sex education limited. Parents communicate negative/misleading information about sex. Previous sex education irrelevant at time. Educated selves from observing and communication with peers. More appropriate sex education desired (e.g. risks, concrete information, unusual sexual activities, reality vs fantasy). 5) Partner accommodation/ negotiation e.g. planning sex, literal communication, alternatives to sex to accommodate needs.
Holmes, Himle, Sewell, Carbone, Strassberg and Murphy (2014), USA.	Evaluate the current practices of, and common barriers of paediatricians addressing sexuality issues and providing sexuality - related care for adolescents and young adults with ASD.	Quantitative. Cross-sectional. Online-survey design.	203 paediatricians (131 female, 72 males; 172 Caucasian) of children (n=192), adolescents (n=181), young adults (n=71). 85% trained in ASD. ASD-focused practice: n=143 1-25% of their practice and n=9 76-100% of their practice.	Online survey (author developed) 67-items, Likert-scales, 3 sections: demographics, sexuality-related topics discussed with individuals with ASD, barriers to sexuality-related care. Questions developed based on American paediatric guidelines and from literature.	Poisson regression - whether demographics and practice variables predicted topics the discussed at least once.  Spearman correlation coefficients - practice variables associated with number of topics discussed.	- Agreed giving information on sexual development (92%) and sexual behaviour (94%) was their role. Average number of topics discussed at least once was 10.6 (range 0-26). Topics regularly discussed: self-care and social skills (82%), emotional maturity (73%), sexual development (67%), impact of cognitive difficulties on behaviour/ social skills (66%), and abuse (54%). Rest of topics discussed at least once by less than half, and if there was a problem. - Few discussed certain topics without parents present (e.g. abuse 25%, reproduction, 26%; contraception, 32%, sexual orientation, 8%, etc.). - Greater experience in ASD significantly increased topics discussed. Barriers: prioritising urgent issues over prevention (67%), lack of information (63%), lack of training (61%), child discomfort (58%), parent discomfort (53%).

Roth and Gillis (2015), USA.	How adults with ASD used online dating services.	Cross-sectional, mixed-methods online-survey design.	17 adults with ASD (6 males, 11 females; 19-50 years old). Self-reported ASD. Sexual orientation; 10 heterosexual, 2 gay or lesbian, 3 bisexual, 1 asexual, and 1 pansexual.	Online Dating Survey (author developed). Self-report, 48 questions (multiple-choice and open-ended). 5 sections; Demographic Information, Online Dating, Previous Relationships, Safety Precautions, Future Education. Asked if interested in learning about 4 further topics on: a) profiles/emails, b) moving from computer communication to face-to-face, c) dealing with rejection / rejecting others, d) identifying frauds/ scams.	Descriptive analyses of quantitative answers five sections of survey.  Conventional content analysis, and inductive approach, to analyse qualitative answers on survey.	9 tried online dating. 46% said it was easier than direct meetings. 56% had long-term relationships from online dating. Benefits: available information, can meet people if dislike face-to-face situations. Drawbacks (answered by 13 participants): Safety (81%), difficulties moving to face-to-face meetings, too many options, dealing with rejection. Safety Precautions (answered by 15 participants): 6 participants said they took precautions to protect themselves, 9 did not use online dating (e.g. altering demographic information). Some took inappropriate safety precautions (e.g. meeting person soon after meeting online). Teaching about safety precautions: 7/15 had been taught about safety precaution: 7 taught selves, 3 learned through Internet, and 3 taught by parents. Most reported appropriate advice from parents. Future Education (answered by 15 participants): 5/10 participants interested in learning about all 4 topics.
Brown-Lavoie, Vecili & Weiss (2014), Canada.	Exploration of differences between sexual knowledge sources, actual knowledge, perceived knowledge, and sexual victimisation in adults with high functioning ASD, compared with individuals without ASD.	Quantitative cross-sectional, survey design.	95 adults with high functioning (HF) ASD (19-43 years old, mean=27.60; 36 females, 58 males; 74 heterosexual, 20 non-heterosexual). - ASD assessed with AQ. - ASD diagnoses: autism (55%), Asperger's syndrome (41%), PDD (4%). 117 adults without ASD (matched on	Demographics questionnaire. AQ: 50-items, using 4-point Likert scales. 5 areas of ASD functioning (social skills, attention switching, attention to detail, communication, and imagination). Sexual Knowledge Sources (author developed) 6 social sources (parents, teachers, peers, romantic partner, religious leader, support worker) and 5 non-social sources (television or radio, magazines, Internet, brochures, and pornography).	2x2 ANOVAs: sources /perceived/ actual knowledge, between groups.  Chi square analyses: compare frequency of victimisation between ASD and non-ASD groups.  Test of multiple mediation: to measure whether	Sexual Knowledge Sources: - Individuals with ASD reported gained knowledge from less social sources and more knowledge from non-social sources in all three knowledge domains (STI's, sexual behaviours, and contraceptives). - Compared to non-ASD individuals, those with ASD: less likely to gain information about STI's, sexual behaviour, and contraceptives from parents, teachers, and peers, more likely to gain knowledge on STI's from television or radio and pornography, and more likely to gain knowledge about sexual behaviours from support workers, religious leaders, brochures, the internet, and television or radio.

			mean age (18-35 years; mean=27.60 years). Scored below clinical cut-off on AQ.	- Sources measured over 3 knowledge areas; STI's, sexual behaviours, contraceptives. Knowledge of Sexual Health Questionnaire-revised (Weinstein, Walsh, & Ward, 2008): 37-items measuring actual knowledge (25 questions relating to STI's, contraception, reproduction), knowledge sources, and self-efficacy. Perceived Knowledge (author developed) 5-items. Perceived knowledge of; sexual health, contraception, risky behaviour. Sexual Experiences Survey (Koss, Gidycz, & Wisniewski, 1987): 10-items relating to victimisation. Reworded for males and females.	risk of sexual victimisation is mediated by actual knowledge, perception of knowledge, and sources of knowledge.  Independent samples t tests	Actual / Perceived Knowledge: Those with ASD has significantly less perceived and actual knowledge than those without ASD. Sexual Victimization: Individuals with ASD (both males and females) were significantly more likely to experience unwanted sexual contact, sexual coercion, and rape, and 78% at least one experience of sexual victimisation, compared to those without ASD (47.4%). Knowledge, social sources, victimisation: - ASD significantly predicts experience of victimisation, less perceived knowledge, less actual knowledge, and fewer social sources. -Less actual knowledge significantly associated with more victimisation.
Holmes & Himle (2014), USA.	Investigate the sex education topics parents discuss with adolescents with high-functioning (HF) and low-functioning (LF) ASD. Whether adolescent characteristics predicted parent-child sexuality communication.	Cross-sectional, quantitative, online survey design.	190 parents (mean age 46.87 years, 92% female, 88.2% Caucasian) of adolescents with HF and LF ASD (12-18 years old; 86.8% male). - Parent-reported ASD. Parent reported IQ: HF ASD: average or above average (IQ 86-116+; 68.9%). LF ASD: slightly below average or borderline (IQ 71-85; 12.6%), 8.4% mild LD/ below average (IQ 56-70), moderate	SRS-2 (Constantino and Gruber, 2012) Parent reported, 65-items, severity of ASD symptoms. Online Sexuality Survey (author developed) 50-items; demographics, child ASD symptoms, parent-child sexuality communication (PCSC), 'number sexuality-related topics covered with their child' (NSTC). Topics (n=39); privacy, sexual abuse prevention, physical development, reproduction, pregnancy and STI prevention, sexual decision-making, relationships, consent/ coercion, and sexual health.	Descriptive statistics  Multiple linear regressions	ASD severity: 89.4% moderate to severe. Significant differences between HF and LF. Parent-reported NSTC and type of topics: - HF ASD: 0-39 topics (mean 21.95). Common topics: privacy (98.5%), private body parts (96.9%), good/bad touch (95.4%), hygiene (93.1%), public/private (91.5%), and male puberty (91.5%). Least common topics; sexual not including intercourse, STIs, condoms, contraception. - LF ASD: 0-38 topics (mean 13.35). Common topics; private parts (94.7%), privacy (89.5%), good/bad touch (91.2%), hygiene (89.5%), and public/private (69.9%). Least common topic; dating, decisions about sex, contraception, and condoms. - Parents of HF ASD adolescents provided significantly greater NSTC, than parents of adolescents with LF ASD. Adolescent age, and

			LD/ far below average IQ (41-55; 4.7%), and severe/ profound LD (IQ <40; 5.2%).			'social cognition' and 'social motivation' significantly predicted NSTC. - LF ASD adolescents; parents covered less advanced topics, which did not become more advanced as their child got older.
Rosqvist (2014). Sweden.	Analysis of the meanings of sexuality and couplehood expressed by adults with autism, analysed via articles in a Swedish magazine for adults with autism, called Empowerment (published between 2002-2009).	Qualitative	Project Empowerment (2001; The Autism and Asperger Association, Sweden) which aimed to increase opportunities for adults with autism to share experiences. The Magazine Empowerment was created by and for adults with autism.	Exploration of the discourses in the Swedish self-advocacy movement: Empowerment Magazine articles.	Inspired by rhetorical and discourse psychological analysis. Reading and rereading material.	Meanings of Autistic Sexuality; - Dominant discourse of sexual difference/autistic sexuality: autistic sexuality is different from sexuality of TD individuals e.g. different sensory perceptions, gender perceptions and emotions. Challenges the impaired autistic sexuality discourse in research. <i>Neuro-normative society (neurotypical's perspectives seen as normal)</i> ; a deficit discourse of autism. Sexual education; discourse in research clashes with discourses in the magazine; sex education it the individual's responsibility, rather than parents or caregivers. Becoming an Autistic Couple: - Importance of an autism-normative sex education. Challenges the asexuality discourse of autism. - Autistic couplehood; importance of individuals in a couple having similar difficulties. Important for relationships between TD individuals and those with ASD to negotiate and understand each other's needs. (e.g. meet at planned times, and regulate their interaction, etc.).
Ballan (2012). USA.	Explore the nature and content of parent communication about sex education, parents perspectives of what knowledge	Qualitative	18 parents (16 female, 3 fathers; including one parent dyad; 84% married) of 20 children with ASD (19 males and 1 female; 6-13 years old; n=12 were 6-9 years old, and n=8 were 10-13 years	In-depth, semi structured, face-to-face interviews: 2 main questions (with probes for examples, clarity, and further information about sexuality topics): 1) "What knowledge and skills are needed for parents to communicate with their children with ASD about sexuality? and	Content analysis of interview transcripts.  Using 2 independent coders. Reliability checks: 94% agreement.	- All parents believed it was their role, and 6 believed it was also professionals' role, to deliver sex education. Parents wanted support and information from health and education professionals. Professionals tend to intervene when sexual behaviour becomes problematic. - Parents (n=16) concerned children's behaviours would be misinterpreted, seen as deviant, stigmatised, or lead to abuse.

	and skills they need for this, and possible barriers to parent-child communication about sexuality.		old). 16/20 attended mainstream school, 4/20 attended partial mainstream/ special education.	2) What types of support are necessary for parents to provide sexuality information to their children with ASD?" (p677).	Themes: 'Misperceptions of Children's Behaviours', 'Challenges Discussing Sexuality with Children and Professionals', 'Sexuality information communicated to children', 'Perceptions of children's future'.	<ul style="list-style-type: none"> <li>- Methods used to reduce inappropriate behaviours; visual, behavioural, symbols, gestures.</li> <li>- 16 parents were comfortable discussing sexuality issues with their children, but wanted to develop skills in sex education.</li> <li>- Child's difficulties was a barrier to sex education.</li> <li>- Some parents believed some topics currently inappropriate for their child e.g. STIs, pregnancy).</li> <li>- Topics focused on safety and cleanliness.</li> <li>- Many did not believe their child would experience future intimate relationships, so avoided some topics (e.g. dating, sex).</li> <li>- Parents of younger children (6-9 years) believed less advance sex education should be late in primary school. Parents of older children (10-13) said more advance sex education should be early in primary school.</li> </ul>
Mehzabin & Stokes (2011). Australia.	To measure the sexual experience, sexual and social behaviour and knowledge of young TD adults compared with young adults with HF ASD.	Cross-sectional, mixed-methods, survey design.	24 adults with HF <i>ASD or Asperger's</i> syndrome (18-30 years old; 12 males, 9 female). 46 TD adults (18-30 years old; 15 males, 24 female).	Sexual Behaviour Scale (SBS; Stokes & Kaur, 2005); Modified from parent-report so participants with ASD could complete. Scales and open-ended questions. 6 sections; 1) Social Behaviour, 2) Privacy, 3) Sex Education; types of sex education knowledge, and sources where learned about sex and relationships, 4) Sexualised Behaviour, 5) Sexual Experience. 6) Future Concerns.	10 cases excluded from the data due to > 5% of missing data. Descriptive statistics. Tests of normality and use of MANOVA.	<p>Quantitative findings:</p> <ul style="list-style-type: none"> <li>- HF ASD adults, compared to TD adults, had significantly less social behaviour, sex education knowledge, sexual experiences, and greater future concerns.</li> <li>- HF ASD and TD adults had similar knowledge about privacy and levels of sexualised behaviour in public.</li> </ul> <p>Qualitative findings:</p> <ul style="list-style-type: none"> <li>- HF ASD adults learned about sex and relationships from additional sources including television, learning from their own errors/themselves, peers, and less so from teachers or parents.</li> </ul>



Table 2: Quality assessment of studies with quantitative methodology

	Corona et al. (2016)	Cunningham et al. (2016)	Hannah & Stagg (2016)	Holmes et al. (2016a)	Holmes et al. (2016b)	Dekker et al. (2015)	Ginevra et al. (2015)	Roth & Gillis (2015)	Brown-Lavoie et al. (2014)	Holmes & Himle (2014)	Holmes et al. (2014)	Mehzabin & Stokes (2011)
1. Question / objective sufficiently described?	2	2	2	2	2	2	1	2	2	2	2	2
2. Study design evident and appropriate?	2	2	2	2	2	2	2	2	2	2	2	1
3. Method of subject/comparison group selection or source of information/input variables described and appropriate?	2	1	1	2	2	2	1	1	1	2	1	2
4. Subject (and comparison group, if applicable) characteristics sufficiently described?	1	2	1	2	2	2	2	2	2	2	2	2
5. If interventional and random allocation was possible, was it described?	N/A	2	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
6. If interventional and blinding of investigators was possible, was it reported?	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
7. If interventional and blinding of subjects was possible, was it reported?	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
8. Outcome and (if applicable) exposure measure(s) well defined and robust to measurement misclassification bias? means of assessment reported?	2	2	2	2	2	2	2	2	2	2	2	2
9. Sample size appropriate?	1	2	2	2	2	0	1	N/A	2	2	1	1
10. Analytic methods described/justified and appropriate?	2	2	2	2	2	2	2	2	2	2	1	1
11. Some estimate of variance is reported for the main results?	0	2	2	2	2	0	2	N/A	2	2	1	2
12. Controlled for confounding?	0	1	1	2	2	0	2	N/A	2	2	N/A	1
13. Results reported in sufficient detail?	2	2	2	2	2	2	1	2	2	2	2	2
14. Conclusions supported by the results?	2	2	2	2	2	2	2	2	2	2	2	2
Total %	72	92*	86*	100*	100*	72	81*	94*	95*	100*	80*	81*

\* Scores <75% cut-point are good quality (Kmet et al., 2004). Scoring: 2=yes, 1=partial, 0=no, N/A=not applicable

NB: Two studies utilising mixed-methods (Hannah & Stagg, 2016; Roth & Gillis, 2015) are presented in both tables.

Table 3: Quality assessment of studies with qualitative methodology

	Dewinter et al. (2017)	Hannah & Stagg (2016)	Mackin et al. (2016)	Barnett & Maticka-Tyndale (2015)	Roth & Gillis (2015)	Roqvist (2014)	Ballan (2012)
1. Question / objective sufficiently described?	2	2	2	2	1	2	2
2. Study design evident and appropriate?	2	2	2	2	2	2	2
3. Context for the study clear?	2	1	2	2	0	2	2
4. Connection to a theoretical framework / wider body of knowledge?	1	2	2	2	0	2	2
5. Sampling strategy described, relevant and justified?	1	1	2	2	1	2	2
6. Data collection methods clearly described and systematic?	2	2	2	2	2	1	2
7. Data analysis clearly described and systematic?	2	2	2	2	1	1	2
8. Use of verification procedure(s) to establish credibility?	2	2	2	2	0	0	2
9. Conclusions supported by the results?	2	2	2	2	2	2	2
10. Reflexivity of the account?	0	1	1	1	0	0	1
Total %	80*	85*	95*	95*	65	70	95*

\* Scores <75% cut-point are good quality (Kmet et al., 2004). Scoring: 2=yes, 1=partial, 0=no, N/A=not applicable

NB: Two studies utilising mixed-methods (Hannah & Stagg, 2016; Roth & Gillis, 2015) are presented in both tables.

### 3.2. Parents

Ten studies presented findings about parent-led sex education. However, caution should be taken in interpreting the findings as most parent participants were female, Caucasian, and married, and individuals with ASD were mostly male, limiting the generalisability of the findings. Five of these studies investigated which variables influenced parent-led sex education, however, three of these studies, assessed as good-quality, were by the same research group (Holmes & Himle, 2014; Holmes, Himle, & Strassberg, 2016b, 2016a). The initial 2014 study investigated the relationship between adolescent (12-18 years old) ASD severity and parent-led sex education; as measured by the number of sex education topics parents discussed with their children. The later studies (Holmes et al., 2016a, 2016b) progressed to investigating the impact of parents' 'concerns' (e.g. their child's ASD-related difficulties negatively impacting intimate relationships), 'expectations' (e.g. about their child's future intimate relationship experiences), and 'feeling of readiness' to support their children's sexual development, on parent-led sex education. All three studies considered the impact of parent-reported intelligence quotient (IQ) on parent-led sex education, two of which (Holmes et al., 2016a; Holmes & Himle, 2014) included parents (n=190) of adolescents with ASD with a full range of IQ levels; including those within the LD range (IQ<70). The latest study only included parents of adolescents (n=131) with average or above average IQ (86-116+; Holmes et al., 2016b). All three studies had large sample sizes, yet they were from the same sample of participants, which may be biased towards a particular demographic in the United States of America (USA). This reduces the generalisation of the findings, and prevents the introduction of natural variance, which would occur if they had included independent samples. Measures included a combination of author-developed online

surveys and validated rating scales. The Social Responsiveness Scale 2 (Constantino & Gruber, 2012) was used to measure overall ASD severity, however, it primarily measures social difficulties associated with ASD, which only partly explains the characteristics of ASD (APA, 2013).

The findings showed that ASD severity did not predict parent-led sex education (Holmes et al., 2014). However, parents of children with more severe ASD symptoms had less hopeful 'expectations' about their children's future intimate relationships (e.g. marriage, sexual experiences), and greater 'concerns' about the impact of their children's difficulties on future intimate relationships (e.g. not getting married, unwanted pregnancies; Holmes et al., 2016a, 2016b). Although parent 'concerns' did not influence parent-provided sex education, they did influence how equipped parents felt to support their children's sexual development (Holmes et al. 2016b). In regards to the influence of adolescent IQ, parents of children with average or above average IQ (86-116), discussed significantly more topics overall, which increased as their child got older, unlike parents of children with below average IQ (<85). Parents of children with average or below average IQ (<85) mostly discussed less advanced topics (e.g. body parts, hygiene etc.; Holmes & Himle, 2014), however, those with more hopeful expectations about their child's future, discussed significantly more topics than parents with less hopeful expectations (Holmes et al., 2016a). This suggests that greater adolescent ASD severity and lower IQ may negatively influence parent-led sex education, particularly if parents have lower 'expectations'. Parents of children with below average IQ may have additional concerns about supporting their children's sexual development (Holmes et al., 2016b).

Secondly, two good-quality qualitative studies interviewed 18 parents of children (6-13 years old; Ballan, 2012), and 15 parents of adolescents and young adults (14-20 years old; Mackin, Loew, Gonzalez, Tykol, & Christensen, 2016), with ASD (diagnosis reported by parents), about the nature of parent-led sex education. Most parents believed it was their role to provide sex education for their children, and had previously done so. Only a quarter of parents believed their children would experience future intimate relationships (Mackin et al., 2016), and many were concerned their children's inappropriate behaviours would be misunderstood, stigmatised, or put them at risk of abuse. To overcome this, parents taught their children about appropriate behaviours (e.g. private or public behaviours), safety from abuse, and personal cleanliness (e.g. because of a reluctance to wash due to sensory sensitivities; Ballan, 2012; Mackin et al., 2016). Parents used a variety of teaching methods, including visuals, symbols, gestures, and conversation. Parents recommended topics their children could benefit from, including, "matters of maturation" (e.g. puberty), "consequences of sexual behaviours" (e.g. pregnancy, legal), and "issues of social navigation" (e.g. social boundaries; p.613; Mackin et al., 2016). Parents reported the barriers to sex education included certain topics seeming inappropriate for their children at the time, feeling unsure how to teach sex education, and having less hopeful expectations of their children's future intimate relationship experiences, due to their ASD-related difficulties (e.g. not having friends, poor comprehension; Ballan, 2012).

The remaining five studies focussed on the perceptions of individuals with ASD about parent-led sex education, which included three questionnaire studies (Brown-Lavoie, Viecili, & Weiss, 2014; Mehzabin & Stokes, 2011; Roth & Gillis, 2015) and two

interview studies (Barnett & Maticka-Tyndale, 2015; Dewinter, Van Parys, Vermeiren, & van Nieuwenhuizen, 2017). Adults with ASD reported parent-led sex education was limited, consisting of more negative than positive information, and was less likely to be a source of their knowledge, compared to TD individuals. Some individuals with ASD reported they were more likely to gain information from other sources, such as the internet. However, only one of these studies formally assessed participants' IQ and ASD (Brown-Lavoie et al., 2014), whereas the others included participants with either self-reported ASD (Barnett & Maticka-Tyndale, 2015; Roth & Gillis, 2015), or did not report the source of this diagnosis (Mehzabin & Stokes, 2011).

### **3.3. Sex education**

Ten studies reported findings on sex education; including outcomes from sex education interventions, previous experiences of sex education, recommendations for sex education, and an alternative perspective of sex education for individuals with ASD.

#### **3.3.1. Formal sex education programmes**

Three studies, assessed as good quality or slightly below (Table 2), employing pre-post experimental designs, investigated the impact of three sex education group-programs (see Table 4) on the knowledge of adolescents and adults with ASD (Corona, Fox, Christodulu, & Worlock, 2016; Cunningham, Sperry, Brady, Peluso, & Pauletti, 2016; Dekker et al., 2015).

Table 4: Sex education program descriptions

Study author(s)	Sex education intervention	Format and content of intervention
Dekker et al. (2015)	Tackling Teenage Training (TTT): A piloted psychoeducational group-program for adolescents (11-19 years, n=30) with ASD and IQ<80.	<ul style="list-style-type: none"> <li>- 18 sessions.</li> <li>- Topics were wide ranging; e.g. puberty, dating, love, sex, pregnancy, social boundaries, etc.</li> <li>- Teaching methods included; realistic visuals and objects (e.g. model penis and condoms, concrete materials), homework.</li> <li>- Teaching alternated with exercises and tests.</li> <li>- Parents given feedback to support generalisation of knowledge.</li> </ul>
Corona et al. (2016)	Piloted psychoeducational sex education group-program (unnamed) for adolescents (12-16 years, n=8) with ASD, and their parents (n=8; 6 mothers, 2 fathers).	<ul style="list-style-type: none"> <li>- 6 sessions, 2 hours each, over 3 months.</li> <li>- Separate adolescent and parents covering the same topics.</li> <li>- The parent sessions included additional teaching; methods to facilitate children's learning e.g. visual aids to teach abstract ideas, ways to communicate about sexuality, and how to maintain their safety.</li> <li>- Topics were wide ranging; e.g. body, puberty, masturbation, privacy, hygiene, relationships, dating, sexual behaviour, safety, legal matters, and communicating via electronic devices, etc.</li> <li>- Teaching methods included; verbal and visual communication, visual schedule, session rules for conduct with rewards.</li> </ul>
Cunningham et al. (2016)	Relationships Enhancement® (RE; Ortwein & Guerny, 2008) group-psychoeducational/ brief-therapy program for romantic relationships. RE-ASD – adapted RE for individuals with ASD by the authors (n=38 adults with ASD; 30 males, 8 females; 18-50 years old).	<ul style="list-style-type: none"> <li>- 2 hours per week for 8 weeks</li> <li>RE: 2 lessons per session</li> <li>RE-ASD: 3 lessons per session</li> <li>- 3 extra lessons to RE (incorporated into allotted time in third, fourth and fifth sessions); relationship initiation (e.g. flirting), judging a person's interest in you, asking someone on a date.</li> <li>- Additional behaviour rehearsal time.</li> </ul>

Intervention outcomes were measured with author-developed questionnaires and rating-scales (e.g. trainer- and parent-rated; Corona et al., 2016; Dekker et al., 2015) or validated self-report measures (Cunningham et al., 2016). Cunningham et al. (2016) randomised participants to groups, to prevent selection bias. However, only one study (Dekker et al., 2015) formally assessed for IQ and ASD.

Dekker et al. (2015) found the Tackling Teenage Training (TTT) significantly increased adolescent knowledge, particularly for younger participants, and their parents reported most adolescents generalised their learning. Individuals rated by trainers to experience more difficulty made significantly larger improvements in their knowledge. However, at pre-treatment, younger participants and those with more difficulties may have begun with less knowledge, meaning greater improvements were seen, yet the authors did not calculate this effect due to a small sample (n=30). Also, the TTT was designed for individuals with ASD and an IQ above 80, yet included participants had IQs of 75 and over. Thus, facilitators received training to adapt the teaching to these participants' needs, yet limited information was provided on the adaptations. Despite this, it suggests those with lower IQ may present with additional needs and require additional sex education adaptations.

Cunningham et al. (2016) found no differences between the Relationships Enhancement® (RE) and the author-adapted RE for individuals with ASD (RE-ASD; Table 4). In both conditions, participants' self-reported 'social skills' and 'empathy' significantly improved, but their 'social support' did not. However, the RE assumes individuals have experienced romantic relationships, yet most participants were



single, and information on relationship history was not provided, possibly limiting the impact of the interventions.

Corona et al. (2016) found no significant improvements in adolescent knowledge or parent comfort with discussing sex education topics. But, parents discussed significantly more topics with their children post-intervention, and most parents (75%) were satisfied with the programme. However, this study excluded individuals with problems with conduct, communication, and group-interaction, limiting the findings' generalisability. Also, the small sample (n=8) may have limited establishing significant findings.

### **3.3.2. Experiences of previous sex education**

Experiences of previous sex education were reported by six good-quality studies; two from the perspective of parents (Ginevra, Nota, & Stokes, 2016; Mackin et al., 2016) and four from the perspective of adolescents and adults with ASD (Barnett & Maticka-Tyndale, 2015; Dewinter et al., 2017; Hannah & Stagg, 2016; Roth & Gillis, 2015). Parent-reports revealed their children with ASD had all previously experienced sex education (n=15; Mackin et al., 2016) and their knowledge improved with age. However, children with ASD displayed more inappropriate sexual behaviour, which their parents had greater concerns about, compared to parents of TD children (Ginevra et al., 2015). Caution should be taken interpreting these finding, as one study over-represented fathers (Ginevra et al., 2015), and the rest over-represented mothers (Table 1). Also, Ginevra et al. (2015) translated a valid parent-report scale (SBS; Stokes & Kaur, 2005) into Italian, and did not report on the actual 'sources' of sex

education despite the ‘Sex Education’ subscale measuring for this, which reduces the findings’ reliability.

Self-reports from adults with ASD, from qualitative interviews (Dewinter et al., 2017; Hannah & Stagg, 2016; Barnett & Maticka-Tyndale, 2015) and an author-developed online survey (Roth & Gillis, 2015), found most were dissatisfied with previous sex education (e.g. in school), had not been taught preferred topics (e.g. online dating safety; Roth and Gillis, 2015), and some did not believe they needed further sex education (Barnett & Maticka-Tyndale, 2015; Hannah & Stagg, 2016), which is surprising considering their dissatisfaction with previous sex education. Also, individuals with ASD had significantly less sexual experience, knowledge and confidence (Hannah & Stagg, 2016), and their first sexual experiences occurred later (15 after 18 years old, and 5 after 30 years old), compared to TD individuals (Barnett & Maticka-Tyndale, 2015). In contrast, interviews with adolescents with high functioning (HF) ASD found most had received sex education in school and were satisfied with its quality (Dewinter et al., 2017). However, males were over-represented in these studies’ samples, reducing the findings’ generalisability to females.

### **3.3.3. Suggestions for future sex education**

Suggestions for future sex education were found by three qualitative interview studies, one from the perspective of parents (Mackin et al., 2016) and two from the perspective of adults with ASD (Barnett & Maticka-Tyndale, 2015; Roth & Gillis, 2015). Parents’ suggested topics should include relationships, sexual activity, boundaries, and the body. Recommended teaching methods included using ASD-

appropriate materials, presenting information in multiple formats (e.g. visually, accessibly written, modelling, repetition), contextualising information to enable generalisation, including the child's values, running the session at the child's pace, using a group format, including parents and providing them with feedback (Mackin et al., 2016). Adults with ASD suggested additional topics should include online dating safety (Roth & Gillis, 2015), preventing abuse, unusual sexual activities, distinguishing 'reality' from 'fantasy', and concrete information about the body (Barnett & Maticka-Tyndale, 2015).

### **3.3.4. Alternative view of sex education**

A qualitative study (Rosqvist, 2014), of slightly poorer quality (see Table 3), conducted an analysis ("inspired by rhetorical and discourse psychological analysis"; p354) of Swedish magazine articles for connotations about 'sexuality and couplehood'. The magazine, called 'Empowerment' (published between 2002 and 2009) was written by and for adults with ASD. The findings provided an alternative perspective to formal sex education's 'deficit' discourse about 'ASD sexuality', instead proposing an emphasis on the value of an 'ASD-normative' sex education, through which individuals can learn from the experiences of other people with ASD and through self-discovery.

### **3.4. Healthcare professionals**

Four studies reported on the role of healthcare professionals in delivering sex education. Only one study (Holmes et al., 2014) directly investigated healthcare professionals', specifically paediatricians', (n=203) delivery of sex education for children, adolescents and adults with ASD. Using an author-developed online survey,

findings showed most paediatricians agreed communicating to young people about sexual development (92%) and behaviour (94%) was part of their role, and all had discussed the sex education topics listed at least once. Topics more regularly covered included 'self-care and social skills' (82%), 'emotional maturity' (73%), 'physical sexual development' (67%), the impact of cognitive difficulties on social skills and behaviour (66%), and the risk of abuse (54%). The least regularly covered topic was sexual orientation (8%). Paediatricians with more ASD-related experience discussed more sexuality topics. However, most paediatricians would not discuss certain topics (e.g. contraception) unless parents were present. Barriers to sex education included prioritising urgent health issues, and poor access to relevant training or resources.

Finally, three qualitative studies, on the perspectives of parents or individuals with ASD, found parents believed healthcare professionals (e.g. paediatricians, psychologists) have a role in delivering sex education, and guiding parents how to provide sex education, because of their expertise in ASD (Mackin et al., 2016; Ballan, 2012). However, parents reported professionals typically intervene when sexual behaviours become problematic (Ballan, 2012). Few individuals with ASD reported they sought information about 'sexual behaviours' from some professionals (e.g. support workers; Brown-Lavoie et al., 2014).

### **3.5. School-based sex education**

No studies directly investigated school-based sex education, however, seven aforementioned studies reported the perspectives of parents and individuals with ASD about previous school-based sex education. Most individuals with ASD had received school-based sex education (Dewinter et al., 2017; Mackin et al., 2016), but many

experienced it as poor (Hannah & Stagg, 2016) and they were less likely to gain knowledge from their teachers, compared to TD individuals (Brown-Lavoie et al., 2014; Mehzabin & Stokes, 2011). Qualitative interviews revealed that adults with ASD (19-61 years old) who received education about reproduction in school had felt irrelevant at the time (e.g. identified as asexual or had no sexual interests). Individuals with ASD reported their preferred topics would have included non-heterosexuality, how sensory sensitivities impact sexual experiences, dating, and recognising less obvious signs of abuse and positive relationships (Barnett & Maticka-Tyndale, 2015).

Two studies reported parents' recommendations for school-based sex education. Parents believed education professionals have a role in delivering sex education to individuals with ASD (Mackin et al., 2016). Parents of younger children (6-9 years old) with ASD suggested that 'basic' sex education (e.g. body parts) should be provided later in primary school, but parents of older children (10-13 years old) with ASD believed 'advanced' sex education should be provided earlier in primary school (e.g. sexual health, masturbation). It may be speculated that parents of older children had preferred their children to experience more advanced sex education earlier as prevention for inappropriate behaviours (Ginevra et al., 2015), whereas parents of younger children may be concerned that sex education could lead to inappropriate sexual behaviour.

### **3.6. Peers**

Six aforementioned studies reported findings that peers were an additional source of sexuality knowledge for individuals with ASD. Adults and adolescents with ASD reported that they learned from their peers by watching and communicating with them

(Barnett & Maticka-Tyndale, 2015; Mehzabin & Stokes, 2011), which encouraged them to discover more about their own sexuality (Dewinter et al., 2017). However, compared to TD individuals, individuals with ASD have less sex and relationships knowledge (Mehzabin & Stokes, 2011), are less likely to learn from peers, particularly about certain topics (e.g. STIs, contraception and sexual activities), and are more likely to learn from the media or internet (Brown-Lavoie et al., 2014; Hannah & Stagg, 2016). These findings suggest peers may be an extra, but not a primary, source of information (Mackin et al., 2016).

### **3.7. Partners**

Four studies reported on the role of romantic partners in supporting individuals with ASD to develop intimate relationships. A questionnaire study revealed that some adults with ASD reported gaining sex education information (e.g. STIs, sexual behaviours, and contraception) from their partners (Brown-Lavoie et al., 2014). Two interview studies with adults (Barnett & Maticka-Tyndale, 2015) and adolescents with ASD (Dewinter et al., 2017) found they felt more positive about their relationships, and less anxious, when partners used literal communication, and successfully negotiated with them to plan sex, engage in sexual experimentation, and participate in alternative activities to sex, to accommodate their sensory needs. Additionally, the aforementioned qualitative analysis of 'Empowerment' magazine articles, found relationships were more successful when couples had similar ASD-related needs (Rosqvist, 2014). Barriers to successful relationships were associated with difficulties with adapting to partners' preferences and interpreting partners' social cues, as well as relationships between individuals with ASD and TD individuals, due to differences in

communication, behaviours, and sensory needs (Brown-Lavoie et al., 2014; Dewinter et al., 2017; Rosqvist, 2014).

### **3.8. Religion**

Two studies (Mackin et al., 2016; Brown-Lavoie et al., 2014) reported that religious leaders could be sources of sex education. Adults with HF ASD (13%) were up to four times more likely to learn about sexual behaviours from religious leaders than TD individuals (4%; Brown-Lavoie et al., 2014). A small proportion of parents (n=3/15) of young people (14-20 years old) with ASD believed the church should play a role in providing sex education. However, these studies were conducted in the USA and Canada, where Christians represent a large proportion of the population, reducing generalisability of these findings to other faiths.

### **3.9. Internet, pornography, and media**

Six studies found the internet, pornography and media (e.g. television, magazines) were sources of sex education for individuals with ASD. Four aforementioned studies, from the perspectives of individuals with ASD and their parents, found books, leaflets, television, the internet and pornography were sources of sexuality information (Dewinter et al., 2017; Mackin et al. 2016; Brown-Lavoie et al., 2014; Mehzabin & Stokes, 2011). Individuals with ASD were more likely to learn about STIs, sexual behaviours and contraception from these sources, yet they had significantly less sex education knowledge (Brown-Lavoie et al., 2014; Mehzabin & Stokes, 2011) and had experienced significantly more occasions of sexual victimisation (78%; e.g. unwanted sexual contact, rape) than TD individuals (47.4%; Brown-Lavoie et al., 2014; see Table 1). An online survey conducted by Roth and

Gillis (2015) found nine out of 17 adolescents reported using dating websites and reported the benefits were the availability of information about their prospective partner before meeting them, they are more manageable than meeting someone directly, and half of these participants had developed a long-term relationship from online dating. However, 81% of 13 of these participants reported ‘safety’ was an issue (e.g. risk of abuse, people falsely representing themselves), so they either learned about online safety themselves (n=7), through the internet (n=3), or from their parents (n=3).

Findings from Rosqvist’s (2014) qualitative analysis demonstrated that through writing magazine articles, individuals with ASD can self-advocate and be a source of information about sexuality as experienced by people with ASD. These findings counteract the “deficit discourse of autism as being deficient... that through education a possibly suitable autistic sexual subjectivity can be developed” (p362, Rosqvist, 2014).

#### **4. Discussion**

This review aimed to synthesise and critique empirical research, which investigated the ‘supports’ and sources of information which facilitate individuals with ASD to develop intimate relationships. The main ‘supports’ and sources in the research were; sex education programmes, parents, health professionals, school, peers, partners, religious leaders, and the internet, pornography and media. A discussion of the main findings is presented, followed by an overall critique of the studies’ methodologies, and implications for clinical practice and future research.



Parents believe providing sex education for their children with ASD is an important part of their role, and are actively engaged in this. However, individuals with ASD prefer not to seek information from their parents, and they experience receiving less sex education from their parents, than their parents report providing them with. Whilst many individuals with ASD reported gaining their sex education knowledge from the internet (Brown-Lavoie et al., 2014), only a few had been taught about online safety by their parents (Roth & Gillis, 2015). Parents were concerned they lacked the skills to deliver adapted sex education (Ballan, 2012; Barnett & Maticka-Tyndale, 2015). Despite this, the value of parent-led sex education is that parents are usually invested in their children's sexual development, and if parents' requests for support from professionals with expertise in ASD is fulfilled, their skills in teaching sex education may improve. This was demonstrated by including parents in a sex education programme (Corona et al., 2016), but the longer-term impact of parent-led sex education on the knowledge and behaviours of individuals with ASD remains unknown. Moving forward, it would be beneficial for parents to elicit their children's feedback, to improve parent-led sex education in meeting their needs.

The influence of IQ of individuals with ASD on sex education provision, is an area of developing interest. Findings suggest that the lower an individual's IQ, the less hopeful their parents are about their future intimate relationships, which reduces parent-provision of sex education. Also, findings suggest that individuals with ASD and covarying LDs, or lower IQ, are likely to have additional needs, for which sex education adaptations are required (Dekker et al., 2015).

Two group-based sex education interventions significantly increased the knowledge of individuals with ASD (Cunningham et al., 2016; Dekker et al., 2015), and one increased the frequency of parent-led sex education (Corona et al., 2016). However, to assess the longer-term impact of these programmes on the knowledge and behaviours of individuals with ASD, follow-up measures are needed. Also, the lack of control groups prevented findings from being compared to other populations or treatment conditions. The findings suggest that some interventions may have been appropriately adapted to the needs of individuals with ASD, which is consistent with their self-reported dissatisfaction of previous sex education (Barnett & Maticka-Tyndale, 2015). Alternatively, sex education may suggest a problematic discourse about ‘ASD-sexuality’, possibly restricting this population from exploring their preferred sexual expressions (Rosqvist, 2014). Going forward, service users should be actively involved in developing sex education programs to better meet their needs.

In many of the studies, wide ranging sex education topics (e.g. the body, puberty, touch, dating, boundaries, relationships, love, sex, pregnancy, contraception, social skills, emotional development, etc.) were covered with individuals with ASD (Corona et al., 2016; Cunningham et al., 2016; Dekker et al., 2015; Holmes et al., 2014; Mackin et al., 2016). Also, individuals with ASD reported preferred additional topics, including online safety, risk, unusual sexual activities, non-heterosexuality, the impact of sensory sensitivities on sexual behaviour, dating, discrete signs of abuse, recognising a positive relationship, and real-life versus fantasy (Barnett & Maticka-Tyndale, 2015; Roth & Gillis, 2015). These topics reflect the need to address the social and sensory needs of individuals with ASD (Aston, 2012; Ballan, 2012).

The overarching methods used to deliver sex education were; visual and verbal information, objects, gestures, clear language, visual timetables, rehearsal, and group rules and rewards to encourage good conduct and boundaries (Ballan, 2012; Corona et al., 2016; Dekker et al., 2015; Mackin et al., 2016). Methods recommended by parents and individuals with ASD included using; accessibly written information, modelling, interactional tasks, concrete descriptions, and technology (Barnett & Maticka-Tyndale, 2015; Mackin et al., 2016). These methods highlight the need to adapt the delivery of sex education to meet the communication and social needs of individuals with ASD. However, there were limited descriptions of these methods and adaptations, so it remains unclear which are most effective for this population's needs.

Healthcare professionals believe they have a role in delivering sex education; a belief also held by parents of individuals with ASD. However, paediatricians reported prioritising more urgent issues over preventative sex education, which may partly explain why parents reported professionals will often provide sex education only when sexual behaviours become problematic (Ballan, 2012; Holmes et al., 2014). Parents and healthcare professionals reported the value of working together to deliver sex education. This is reflected in reports from paediatricians who value parents being present during the delivery of sensitive topics (Holmes et al., 2014), and parents express a need for professional guidance on enabling sex education to meet their children's ASD-related needs (Ballan, 2012; Mackin et al., 2016). Overall, there is a paucity of research on professionals' roles in delivering sex education. This is an area worthy of further scrutiny, as those with expertise in ASD may be more equipped to adapt sex education to the unique needs of this population, which is particularly

important when individuals with ASD report preferring not to receive sex education from their parents.

The internet is an evolving theme within the reviewed research, as many individuals with ASD prefer to seek information online (Brown-Lavoie et al., 2014; Roth & Gillis, 2015). As accessing the internet relies less on social interaction, it may feel more manageable than seeking information from people (Hannah & Stagg, 2016). Yet this raises concerns about online safety, particularly when individuals with ASD are at greater risk of exploitation and victimisation (Roth & Gillis, 2015), and not all information available online can be guaranteed to be credible or accurate. This is another area worthy of greater scrutiny, particularly as the internet is a preferred, and possibly vital, source of information for individuals with ASD as it may accommodate their ASD-related needs.

Emerging from the research is the role of peers, partners, and religious leaders as supports or additional sources of information about sex and relationships (Mackin et al., 2016; Rosqvist, 2014). Peers appear to be more of an additional, but not a consistent, source of information for individuals with ASD (Dewinter et al., 2017), which is unsurprising due to individuals with ASD often experiencing difficulties with interpreting social cues and learning implicitly (Hannah & Stagg, 2016). Also, there is some suggestion that religious leaders may provide information on sexual behaviours, although the impact of this on the knowledge of individuals with ASD remains unknown (Brown-Lavoie et al., 2014). Importantly, partner-negotiation and accommodation of the needs of individuals with ASD may facilitate a successful intimate relationship, although, unsurprisingly, those in relationships with TD

individuals find adapting to their partners needs more difficult (Brown-Lavoie et al., 2014; Dewinter et al., 2017; Rosqvist, 2014). Therefore, it may be helpful to incorporate issues of partner negotiation and accommodation into sex education, particularly for neurotypical partners of people with ASD.

Notably in the research is the inclusion of children, adolescents and adults. This suggests that individuals with ASD may require sex education at different developmental stages, which come with new challenges. This is particularly important for individuals with ASD, due to their tendency to think in concrete ways, as taught information will need to feel relevant to their developmental stage, and self-perceived needs, to be applied (Barnett & Maticka-Tyndale, 2015).

Overall, it is not clear where individuals with ASD receive the most effective support for developing intimate relationships, but it is likely to be combination of multiple sources and modalities. However, greater integration between parents, professionals, and service users is required to ensure that parents feel supported, service users' needs and preferences of supports are met, and professionals are trained and apply their knowledge of ASD to effectively adapting sex education to meet service users' needs.

#### **4.1. Overall critique of the studies**

Most of the studies were high quality (see Table 2 & 3), however, some methodological constraints reduced the strength and generalisability of the findings. In the samples, most recruited individuals with ASD were male and Caucasian, and their parents were primarily female, Caucasian, and married. Also, four studies were conducted by Holmes and colleagues, suggesting a bias towards a particular

demographic (Holmes et al., 2016a, 2016b; Holmes & Himle, 2014). These factors impact the generalisability of the findings and prevents determining the impact of participant demographics on the provision and outcome of sex education.

Sample sizes varied greatly, and many studies incorporated small samples which reduced detection of significant findings (e.g. Corona et al., 2016; Dekker et al., 2015). Also, most participants had self-selected to take part in the research, which may suggest they are more comfortable with discussing sexuality issues than those who do not volunteer. An equal number of studies recruited adolescents and adults, with two studies also reporting on younger children (Ballan, 2012; Holmes et al., 2014), however the cut-off age ranges for adults included in the studies varied greatly across studies. Also, the sex education needs of the different developmental groups cannot be determined from these findings.

Only three studies formally assessed participants for ASD (Brown-Lavoie et al., 2014; Dekker et al., 2015; Dewinter et al., 2017), and the rest were self- or parent-reported diagnoses, which may have been imprecise. Some studies reported that individuals had specific ASD diagnoses, including PDD-NOS, Asperger's syndrome, and autism (Brown-Lavoie et al., 2014; Corona et al., 2016; Dekker et al., 2015; Holmes et al., 2016a; Mackin et al., 2016), however, the impact of these different diagnoses on the findings were not considered. Also, over half the studies were conducted in the USA, with the remainder from other Western countries, which may hold culturally-bound understandings about ASD and sexuality. This could influence how individuals with ASD are supported with developing intimate relationships.

Only one study formally assessed for IQ (Dekker et al., 2015), and two officially included individuals with a full range of IQs, including within the LD range (<70; Holmes et al., 2016a; Holmes & Himle, 2014). The remaining studies either formally excluded individuals with IQs below average, assumed an absence of LDs based on education history, or did not report it at all. These studies were likely to have excluded a large proportion of the ASD population, considering approximately a third have covarying LDs (Baird et al., 2006; Fombonne et al., 2009). Although some studies considered the role of IQ in sex education (e.g. Holmes et al., 2016a), limited consideration was made to the impact of covarying LDs on how sex education needs to be adapted to meet their unique needs.

All studies used a combination of validated measures and author-developed measures, or adapted versions of valid measures (e.g. Ginevra et al., 2015), which may reduce the validity of the findings. Studies measuring the provision of sex education did so by the number of topics discussed with individuals, which does not encapsulate intricacies of how these topics were communicated (Holmes et al., 2016a, 2016b). Although self-report data from parents, professionals, and individuals with ASD provided valuable information on their experiences, it can be subject to social desirability bias, and decrease the validity and reliability of the findings. Also, it may be possible that individuals with ASD lacked insight into their needs and difficulties, which may have explained some differences between self- and parent-reports.

#### **4.2. Clinical implications**

Despite the variety of supports available, the sex education knowledge of individuals with ASD is significantly lower than TD individuals (Brown-Lavoie et al., 2014).

There is a need to develop sex education programmes and resources, in school and health services, which are better adapted to meet the unique needs of individuals with ASD. Additional consideration may be needed to address the impact of individuals' possible sensory needs, social difficulties, unusual interests, and non-heterosexual preferences on intimate relationships, to enable them to develop their preferred sexual identity. This is particularly important for individuals with ASD, who show greater levels of gender variance and dysphoria, and are increasingly being referred to gender identity clinics (Glidden, Bouman, Jones, & Arcelus, 2016; May, Pang, & Williams, 2017).

Given that individuals' IQ can influence the provision of sex education, further consideration for on adapting sex education for individuals with ASD and covarying LDs (ASD-LD) is needed, particularly as they form a large proportion of the ASD and LD populations (Baird et al., 2006; Fombonne et al., 2009). As those with ASD-LD have additional needs, compared to those with ASD and LD (Matson & Shoemaker, 2009), adaptations to sex education will need to consider the impact of these individuals combined difficulties on their ability to learn and manage intimate relationships.

Considering the inconsistencies of sex education provision for people with ASD, development of policy outlining best practice is needed, particularly for adults and within healthcare, as existing policy is focused upon schools (e.g. National Autistic Society, 2016). Healthcare and education professionals should be provided with training to increase their competencies with delivering sex education (Holmes et al., 2014) and supporting parents to deliver sex education. There is also scope for



developing sex education programs for parents (Corona et al., 2016), but also neurotypical partners of adults with ASD. Service user involvement in developing sex education programmes, training parents and professionals, and developing media-based, online resources, may increase the satisfaction of individuals with ASD with, and the quality of, sex education provision.

The internet is a preferred source of sexuality information and dating sites and is a preferred method of meeting prospective partners for some (Hannah & Stagg, 2016; Mehzabin & Stokes, 2011; Roth & Gillis, 2015). There is a growing number of dating sites designed for people with ASD (e.g. “Aspie Singles”), therefore, it would be important for the sites to provide clear information, signposting to credible supports, and guidance on face-to-face meetings and safety (Roth & Gillis, 2015).

### **4.3. Research implications**

Further research is required on the most effective methods of developing the knowledge and skills of individuals with ASD to develop meaningful intimate relationships. Generally, a greater consideration is needed on the influence of gender on sex education needs, based on the range of gender identities of individuals with ASD (McNelles & Connolly, 1999), and lack of females represented in the research. There is also a need for more longitudinal studies, utilising valid measures, to investigate the impact of supports (e.g. parent communication about sexuality, sex education programs, non-social sources such as the internet) on, not only the knowledge and skills of individuals with ASD, but their ability to apply their learning to practice in the long-term. The research suggests that adults with ASD still have limited sexuality knowledge, and many report their first sexual experiences occur

after the age of 18 (Barnett & Maticka-Tyndale, 2015), therefore a consideration of all age groups in future research is required.

However, considering the lack of research with professionals with expertise in ASD, who are commonly responsible for delivering sex education interventions in practice, there needs to be research which investigates what has proven to be effective in practice. Importantly, given the limited descriptions of methods used to teach sexuality topics, research is required to determine the most effective methods. Also, those with ASD-LD have been neglected from the sex education literature, with a focus currently on those with LDs (Schaafsma, Stoffelen, Kok, & Curfs, 2013; Sullivan & Caterino, 2008). Therefore, an area worthy of greater scrutiny is how sex education can be adapted to meet the unique needs of those with ASD-LD.

Therefore, future research could investigate:

- Professionals' views of methods for adapting sex education for adults with ASD-LD.
- Longitudinal impact of parent-child communication about sexuality on knowledge, skills, and behaviours of individuals with ASD.
- The impact of gender on the sex education preferences and needs of individuals with ASD.
- The role of the internet and online dating on the sexual behaviours and knowledge of individuals with ASD.

#### **4.4. Conclusion**

Since Gougeon's (2010) review, seventeen studies, most assessed as good quality (n=14; Kmet et al., 2004), have reported findings on the supports and sources of

information that facilitate individuals with ASD to develop intimate relationships. These included, parents, sex education programs, healthcare professionals, schools, peers, partners, and the internet, pornography and media. The findings suggest that individuals with ASD access a variety of supports and sources of information which might facilitate their development of intimate relationships; however, their knowledge remains poor compared to TD individuals. Parents and professionals reported an active role in delivering sex education, and sex education programmes have been proven effective at increasing the knowledge of individuals with ASD. However, individuals with ASD report dissatisfaction with the quality of sex education. Peers appear to be an additional source of information, and romantic partners have a role in accommodating for the unique needs of individuals with ASD to increase the success of intimate relationships. The internet appears to be a preferred source of information on sex and relationships issues for individuals with ASD. However, it remains unclear where individuals with ASD received the most effective support from. The future clinical and research implications of these findings have been presented.

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**Section B:  
Sex Education for Adults with Autistic Spectrum Disorder and Learning  
Disabilities: A Delphi Study**

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A thesis submitted in partial fulfilment of the requirements of  
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SALOMONS  
CANTERBURY CHRIST CHURCH UNIVERSITY

### **Abstract**

Research suggests that individuals with autistic spectrum disorder (ASD) and learning disabilities (LD) experience difficulties in developing meaningful intimate relationships, and mainstream sex education is not adapted to meet their needs. However, ASD and LD frequently co-occur (ASD-LD), and findings suggest this population has unique needs, compared to those with ASD or LD. There is a paucity of research on how sex education should be adapted for individuals with ASD-LD. This study aimed to explore the views of 21 health and social care professionals, experienced in delivering sex education for adults with ASD-LD, on which characteristics of adults with ASD-LD should be considered when providing sex education, and what adaptations to sex education are thus required. To seek whether a group consensus between professionals could be gained, an electronic, three round, Delphi method was used. Findings showed that professionals agreed on the unique characteristics of adults with ASD-LD, and the various adaptations to sex education required, which differed for adults with ASD or LD. The most important characteristics and adaptations primarily related to communication needs, cognitive and executive functions, social impairments, and sensory needs. The clinical and research implications of the findings are presented.

Key words: Autistic spectrum disorder, learning disabilities, sex education, adaptations, Delphi



## **1. Introduction**

Research shows individuals with autistic spectrum disorder (ASD) and learning disabilities (LD) have a desire for intimate relationships and show typical sexual development (Gougeon, 2009, 2010). The ‘Valuing People Now’ White Paper stressed that people with LD and ASD have the right to intimate relationships and sex education which meets their unique needs (Department of Health, 2009).

### **1.1. Autistic spectrum disorder**

ASD is defined, in the Diagnostic and Statistical Manual 5th edition (DSM-5), as a neurodevelopmental disorder encompassing impairments in social interaction and communication, rigid interests, stereotyped behaviours, sensory deficits, and concrete thinking tendencies. ASD includes specific disorders; autistic disorder, Asperger’s disorder, childhood disintegrative disorder, and pervasive developmental disorder-not otherwise specified (American Psychiatric Association, APA, 2013).

### **1.2. Learning disabilities**

LD<sup>2</sup> in the DSM-5 are defined as substantial impairments in intellectual and adaptive functioning, present before adulthood (APA, 2013).

### **1.3. Co-occurring ASD and LD**

Although prevalence rates vary, ASD and LD frequently co-occur (hereon referred to as ‘ASD-LD’). Approximately 50% to 70% of individuals with ASD also have LD

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<sup>2</sup> Now referred to as ‘intellectual disabilities’ by the British Psychological Society (2015), but the term LD is the norm in United Kingdom policy, so will be used throughout. Adaptations for publications will be made accordingly.

(Baird et al., 2006; Fombonne, Quirke, & Hagen, 2009) and a third with LD also have ASD (Brugha et al., 2016; Bryson, Bradley, Thompson, & Wainwright, 2008; Emerson & Baines, 2010). A limited, but growing, body of research has focused on the interaction between ASD and LD, showing these groups share some similar characteristics, but that individuals with ASD-LD are a distinct group with unique needs (Matson & Shoemaker, 2009).

Overall, more severe LD has been found to exacerbate an individual's ASD-related symptoms (Hattier, Matson, Tureck, & Horovitz, 2011; McCarthy et al., 2010).

Individuals with ASD are believed to have an impaired 'theory of mind', due to their difficulties with empathy, considering others' perspectives, and social impairments (Baron-Cohen, Leslie, & Frith, 1985). Individuals with ASD-LD have been found to have greater social impairments than individuals with LD or ASD (Matson, Dempsey, & LoVullo, 2009; Wilkins & Matson, 2009).

Individuals with ASD are thought to have a weak 'central coherence', causing difficulties with global information processing, applying information to context, a resulting concrete thinking style (Happé & Frith, 2006), and executive functioning deficits (Barnard, Muldoon, Hasan, O'Brien, & Stewart, 2008). A weaker central coherence has been found in those with ASD-LD (van Lang, Bouma, Sytema, Kraijer, & Minderaa, 2006). This has been associated with greater difficulties in working memory, information processing and problem solving, than in those with LD (Barnard et al., 2008; Mottron, Morasse, & Belleville, 2001), and greater communication difficulties, than those in with ASD (Noens & van Berckelaer-Onnes, 2004).

Sensory processing deficits are experienced by some individuals with ASD and LD. However, findings suggest that individuals with ASD-LD experience greater sensory processing difficulties, compared to those with LD (Joosten & Bundy, 2010). Overall, whilst some overlaps in difficulties are seen in those with ASD or LD, the findings suggest individuals with ASD-LD may have additional needs.

#### **1.4. Sexuality and intimate relationships**

Individuals with LD and ASD have been shown to have limited knowledge about sex and relationships (Borawska-Charko, Rohleder, & Finlay, 2016) and that their first sexual experiences occur later than typically developing (TD) individuals (Barnett & Maticka-Tyndale, 2015). Without appropriate sex education, individuals with LD and ASD can be at greater risk of, and show high incidences of social isolation (Sullivan & Caterino, 2008; Szanto et al., 2012), mental health difficulties (Hagopian & Jennett, 2008), contracting sexually transmitted diseases, unwanted pregnancies (Potvin, Brown, & Cobigo, 2016), sexual victimisation (Brown-Lavoie, Vecili, & Weiss, 2014) and sexual abuse, than those without disabilities (Jones et al., 2012).

Some individuals with ASD have been found to display more inappropriate sexual behaviours than TD individuals (e.g. stalking; Stokes, Newton, & Kaur, 2007), leading to the perception they are deviant or perpetrators of sexual assault (Hellemans, Roeyers, Leplae, Dewaele, & Deboutte, 2010). Yet, findings suggest that inappropriate behaviours partly arise from difficulties with understanding social rules experienced by individuals with ASD (Stokes et al., 2007). Also, sensory sensitivities can lead to individuals with ASD experiencing sexual contact as aversive, or seeking sensory fulfilment through dangerous sexual behaviours (Hellemans, Colson,

Verbraeken, Vermeiren, & Deboutte, 2007). Without support, this population is likely to have difficulties with navigating the various challenges arising throughout sexual development (O'Brien & Pearson, 2004; Sullivan & Caterino, 2008).

### **1.5. Adapting interventions**

The limited research suggests that therapeutic interventions require adaptations for individuals with LD and ASD. Cognitive Behavioural Therapy (CBT) has been adapted through using Makaton symbols to support the understanding of emotions of individuals with LD (Dagnan, Chadwick, & Proudlove, 2000), and adopting a focus on social coping skills for individuals with ASD (Binnie & Blainey, 2013).

Adaptations to psychodynamic therapy, for individuals with LD, have included using more non-verbal communication (Stavrakaki & Klein, 1986) and more cautiously delivering interpretations (Johnson, Mason, & Withers, 2003). Systemic family therapy adaptations have included slowing the sessions' pace and using visual aids for people with LD (Baum & Lynggaard, 2006; Fidell, 2000). However, the literature provides little insight into intervention adaptations for those with ASD-LD.

### **1.6. Sex education**

Mainstream sex education relies on complex information to be understood, and is not adapted to the needs of those with ASD and LD (Whitehouse & McCabe, 1997).

However, sex education provided to those with ASD or LD is often a reactive strategy to reduce problematic sexual behaviours (Brown-Lavoie et al., 2014; Schaafsma, Stoffelen, Kok, & Curfs, 2013). Although limited, research has focused more on sex education for individuals with LD, than individuals with ASD (Schaafsma et al., 2013; Travers & Tincani, 2010).

Sex education for individuals with LD has been found to improve their capacity to make decisions about sexual behaviour (Dukes & McGuire, 2009). Previous research found sex education adaptations for individuals with LD have included role-play, modelling, rehearsal, feedback, reinforcement, pictorials, discussions, and using individuals' preferred communication methods (Finlay, Rohleder, Taylor, & Culfear, 2015; Schaafsma et al., 2013). Sex education topics have often focused on the functions of sex, and neglected the pleasure of sex and intimate relationships (Kelly, Crowley, & Hamilton, 2009). Although the sex education literature for people with LD is growing, there remains limited detail on the most suitable sex education adaptations (Dukes & McGuire, 2009; Schaafsma et al., 2013).

Sex education for individuals with ASD has been found to increase empathy, social skills (Cunningham, Sperry, Brady, Peluso, & Pauletti, 2016), and knowledge (Dekker et al., 2015). Adaptations to sex education have included, or have been recommended to include visual and verbal information, gestures, simplified language (Corona, Fox, Christodulu, & Worlock, 2016; Dekker et al., 2015), concrete descriptions, modelling (Mackin, Loew, Gonzalez, Tykol, & Christensen, 2016), normalising difficulties, teaching appropriate behaviours, and addressing sensory sensitivities (Barnett & Maticka-Tyndale, 2015). Social Stories (Gray, 2000) have been recommended as an adaptation, as they can increase the interpersonal skills and understanding of social rules of individuals with ASD (Tarnai & Wolfe, 2008). Individuals with ASD and below average IQ (<85) have required additional adaptations to sex education, compared to those with above average IQ (>85);

however, limited descriptions of adaptations were provided (Dekker et al., 2015). Overall, there is a paucity of research on sex education for individuals with ASD.

Individuals with LD and ASD are often reliant on others to provide them with adapted sex education (Dewinter, Vermeiren, Vanwesenbeeck, & van Nieuwenhuizen, 2013). Although parents have been found to actively provide sex education, they feel ill-equipped to, and seek guidance from professionals (Ballan, 2012). However, individuals with ASD and LD have reported dissatisfaction with parent-led (Brown-Lavoie et al., 2014) and school-led sex education (Barnett & Maticka-Tyndale, 2015; Healy, McGuire, Evans & Carley., 2009). Health and social care professionals with expertise in ASD and LD are likely to be equipped to adapt sex education to this population's unique needs, however, there is a paucity of research in this area (Gougeon, 2009; Holmes et al., 2014). Overall, individuals with ASD and LD can be vulnerable, and a lack of sex education has been associated with greater risk and difficulties with developing intimate relationships. Thus, these populations require adaptations to sex education to meet their unique needs.

### **1.7. Rationale for current study**

Despite the paucity of research on adapting sex education for individuals with ASD-LD, experienced professionals work daily in this area. This existing expertise has so far been neglected in the research. Therefore, this study aimed to identify whether experienced professionals could reach consensus about the unique characteristics of those with ASD-LD, and the associated adaptations to sex education required. Adults with ASD-LD were focused upon, considering their difficulties pervade into

adulthood. The findings could inform future recommendations, and prompt further research in this area.

This study adopted an exploratory approach to address the following research questions:

- 1) What are the specific characteristics of adults with ASD-LD that should be taken into consideration when providing sex education?
- 2) What adaptations, if any, do professionals consider should be made to facilitate the delivery of sex education for adults with ASD-LD?

## **2. Methodology**

### **2.1.Design**

This study used a three-round, electronic Delphi method to explore the opinions of experienced health and social care professionals on the important characteristics of adults with ASD-LD, for whom adaptations to sex education are required. The Delphi method enables the development of group consensus on a topic via iterative rounds of questionnaires, where each questionnaire's results informs the development of the next (Powell, 2003). Typically, a qualitative, open-ended, Round 1 Questionnaire (R1Q; Appendix B) generates initial ideas from a group of panellists. R1Q's responses are analysed and generated into statements which represent group opinion. In Round 2 Questionnaire (R2Q; Appendix C) panellists rate their level of agreement with these statements. Round 3 Questionnaire (R3Q; Appendix D) typically involves panellists viewing the overall group ratings of the same statements from R2Q, and re-rating the statements if they wish, or clarifying areas of divergence and consensus (Iqbal & Pison-Young, 2009).

This study adopted a three-round Delphi method, which is considered ideal to gain consensus (Powell, 2003; Sumsion, 1998) and enables an exploratory approach for a topic with a minimal evidence-base (Akins, Tolson, & Cole, 2005). An electronic Delphi method offers additional benefits to a study of this nature, encompassing a greater inclusion of panellists who are distantly located from one another, and enabling anonymous communication of group views (Akins et al., 2005).

## **2.2.Panellist recruitment**

The Delphi method involves purposive sampling of ‘experts’ in the field. ‘Expertise’ is based upon adequate experience with the topic area (Hardy et al., 2004; Powell, 2003). ‘Sex education’ was defined as the direct advice of matters of sexual behaviour and relationships for adults with ASD-LD, through formal programmes or less formalised interactions. Given the paucity of research on the current topic, this study recruited panellists based upon a broad definition of ‘expertise’ and the following inclusion criteria:

- A health or social care professional currently working in or with specialist ASD or LD services who had provided ‘sex education’ for at least 4 adults with ASD-LD, over the last 2 years.

or

- A health or social care professional who has provided training, developed policy, provided supervision, or provided consultation for other professionals / care staff within the area of sex education for adults with ASD-LD, for at least 2 years.

or



- Not currently working in or with specialist ASD or LD services, but had previously provided 'sex education' for a minimum of 10 adults with ASD-LD, throughout their career.

Snowball and purposive sampling was also used to recruit panellists. Initially, the researcher's and research supervisors' networks were contacted, and sent invitation emails (Appendix E), the study information sheet (Appendix F) and an advertisement flyer (Appendix G). Furthermore, various ASD, LD, and sexual health charitable organisations were contacted via email. The flyer was displayed in various LD services and conferences to advertise the study. The researcher also presented the study at a nurses' training event. All who were contacted were asked to circulate the study information to those who may meet the criteria. Interested parties contacted the researcher via email.

A specific profession was not recruited, as sex education provision for this population is currently multi-disciplinary, and richer data may be gained from diverse expertise (Page, 2007). Panellists were also required to be English speaking and commit to three rounds of questionnaires and communication via email.

There is currently no sample size agreement in the Delphi method (Akins et al., 2005). Between 10 and 50 panellists has been recommended (Linstone & Turoff, 2002), however, 10 to 15 panellists are considered adequate for gaining consensus (Taylor-Powell, 2002), particularly when the sample is fairly homogenous (Keeney, McKenna, & Hasson, 2010). Therefore, the present study aimed to recruit between 15

and 50 panellists, to allow for possible attrition (Akins et al., 2005; Hackett, Masson, & Phillips, 2006).

### **2.3.Panellists**

Overall, 21 panellists completed R1Q, 15 completed R2Q, and 14 completed R3Q.

Also, 12 panellists completed all three questionnaires. Panellists who completed R1Q were sent the following questionnaires even if they had not completed preceding ones, but none formally dropped out. Panellist demographics and completion rates are presented in Table 5.

Table 5: Panellist demographics and frequencies of questionnaire completion

Panellist demographics		R1Q (n=21)	R2Q (n=15)	R3Q (n=14)
Current professional role	Clinical psychologist	10	10	9
	LD nurse	6	2	3
	Sexuality counsellor	2	2	0
	Sexual health charity director	1	0	0
	Challenging behaviour specialist	1	1	1
	Social worker	1	0	1
Current service setting	Specialist LD Team	16	11	13
	Assessment and Treatment Team	3	3	0
	Government Disability Services	1	1	1
	Sexual health charitable sector	1	0	0
Years of experience working with adults with ASD-LD	5-9	3	3	3
	10-19	7	5	5
	20-29	5	4	3
	>30	6	3	3
Number of adults with ASD-LD provided sex education for	4-9	5	4	4
	10-19	3	2	3
	20-29	4	3	1
	30-39	2	2	2
	40-49	1	0	1
	50-59	1	0	0
	60-69	1	1	1
>70	4	3	2	
Other roles relating to sex education for adults with ASD-LD*	Consultation with other professionals	16	10	9
	Training	12	8	6
	Supervision of other professionals	11	9	6
	Resource development	7	3	3
	Producing policy	4	2	1
	Research	4	1	2
	None of the above	2	2	2
Ethnicity	White British	14	10	9
	Any other White background	3	3	3
	Irish	1	0	0
	Indian	1	1	0
	Black Caribbean	1	1	1
	Any other ethnic group	1	0	1

\* Panellists could select >1 option, resulting in greater frequencies.

## **2.4.Ethics**

Full ethical approval was granted by a university ethics committee (Appendix H).

Interested parties were given the opportunity to contact the researcher with questions, before completing an electronic consent form (Appendix I). Panellists were allocated a numerical ID to anonymise their responses, and were informed that their identifiable information would be kept confidentially and stored on an encrypted memory stick.

Panellists were asked not to include any identifiable information within their responses, and their anonymous responses would be shared with other panellists and included in the study's report and publication. Panellists received a summary of the results on completion of the study (Appendix J).

## **2.5.Procedure**

Qualtrics Research Suite survey software was used to create and email the questionnaires to panellists. Panellists were given three to four weeks to complete each questionnaire, each taking 20 to 35 minutes to complete. Reminder emails were sent 2-weeks and 1-week before the deadline.

Due to the evolving nature of the Delphi method, more detail on the development and analysis of R1Q is outlined below (section 2.6.), and the development and analysis of R2Q and R3Q is detailed in the results section. In summary, R1Q was constructed based on relevant literature and to broadly address the topic area. The main ideas from R1Q were reduced into statements which formed the basis of R2Q. In R2Q panellists rated their agreement with these statements, and answered additional open-ended questions. As most statements in R2Q achieved consensus (see section 3.1.), R3Q involved panellists clarifying some areas of divergence and consensus from R2Q, and

speculating on a selection of results. In all questionnaires, panellists could add further comments.

## **2.6.R1Q development**

R1Q (Appendix B) included one five-point Likert scale and three open-ended questions (Figure 2). To provide a context to the ‘adaptations’, panellists were also asked which sex education ‘topics’ are important.

Figure 2: R1Q questions

1. Please rate your agreement with the following statement: “Sex education specifically for adults with ASD-LD is important” (‘strongly agree’, ‘agree’, ‘neither agree nor disagree’, ‘disagree’, or ‘strongly disagree’).
2. Which sex education topics are important for adults with a combination of ASD-LD?
3. What adaptations should be made to sex education for adults with ASD-LD? (Please consider both content and delivery methods).
4. How do these adaptations relate to the characteristics of adults with ASD-LD? (i.e. Why these adaptations are important for this particular population).

## **2.7.R1Q analysis**

### **2.7.1. Quantitative data**

Likert scale ratings were analysed using descriptive statistics and consensus calculations. Firstly, as in similar previous research (e.g. Hackett et al., 2006), the data from the five-point Likert scales were reduced into three categories indicating the level of agreement among panellists; ‘agreement’ (amalgamation of ‘strongly agree’ and ‘agree’ ratings), ‘neutral’ (‘neither agree nor disagree’ ratings), and ‘disagreement’ (amalgamation of ‘disagree’ and ‘strongly disagree’ ratings).

Consensus calculations were then conducted for each statement, where the total percentage of each agreement category (agreement, neutral, or disagreement) was

allocated to a corresponding consensus category (Table 6). Consensus was defined when the majority of panellists (>50%) agreed on a particular response, and consisted of four levels of strength (Table 6; adapted from Hackett et al., 2006 and Vosmer, Hackett, & Callanan, 2009).

Table 6: Consensus calculations

Consensus categories	Percentage of panellists' ratings
High consensus	$\geq 80\%$
Medium consensus	65%-79%
Low consensus	50%-64%
No consensus	$< 50\%$

### 2.7.2. Qualitative data

Qualitative data were thematically analysed (Braun & Clarke, 2006; Hackett et al., 2006), by thoroughly reading responses and coding data extracts relating to the research questions. Data extracts were coded when at least two data extracts related to a code. Similar codes were grouped together into significant themes. The codes derived from R1Q's analyses were generated into statements for R2Q (see section 3.2.; examples of theme development in Appendix K).

### 2.8. Quality assurance

Each questionnaire was piloted with two healthcare professionals experienced in working with people with LD or ASD, and two research supervisors. During the thematic analysis, possible researcher bias was accounted for by repeatedly refining the themes, and the themes were audited by two research supervisors.

### 3. Results

#### 3.1.R1Q results

##### 3.1.1. Importance of sex education for adults with ASD-LD

A high agreement consensus was achieved between panellists (n=20, 95.23%) that “sex education specifically for adults with ASD-LD is important” (n=1 rated as ‘neutral’). The thematic analysis revealed themes pertaining to individuals having the right to experience intimate relationships, “People with ASD and LD have as much right to a fulfilling and safe sex life” (Panellist 10). Themes arose about potential risks resulting from not receiving sex education, “The risk of exploitation with this group of people is very high” (Panellist 13), and that mainstream sex education was not as accessible for adults with ASD-LD;

“Adding the further complication of a learning disability means that the individual may not be able to access generic sex education provided elsewhere, as this may be too brief or assume that the person can understand complex concepts” (Panellist 10).

The importance of adapting sex education to individual needs emerged as a theme, “One size does not fit all. So ensure the delivery of education is tailored to the individual” (Panellist 8).

##### 3.1.2. Summary of qualitative responses

Significant themes emerging from R1Q were organised into four categories, pertaining to the key elements of sex education interventions in clinical practice. These included; important ‘Characteristics’ of adults with ASD-LD, ‘Assessments’ to be conducted prior to intervention, ‘Topics’, and ‘Adaptations’ (Table 7).

Table 7: Categories and significant themes from R1Q

Category	Themes
Assessment	<ul style="list-style-type: none"> <li>Assess needs and preferences of individual</li> <li>Assess for allocation to group or individual intervention</li> <li>Assess cognitive abilities</li> <li>Assess communication</li> <li>Assess current knowledge</li> <li>Assess for sensory sensitivities</li> <li>Assess for potential emotional impact and timing of sex education</li> <li>Risk assessment</li> <li>Assess mental capacity</li> </ul>
Characteristics	<ul style="list-style-type: none"> <li>Concrete thinking</li> <li>Communication difficulties</li> <li>Memory difficulties</li> <li>Information processing difficulties</li> <li>Executive functioning difficulties</li> <li>Interpersonal difficulties</li> <li>Difficulties with empathy and theory of mind</li> <li>Difficulties anticipating consequences of behaviours</li> <li>Capacity</li> <li>Emotional difficulties</li> <li>Sensory sensitivities</li> <li>Need for predictability</li> </ul>
Topics	<ul style="list-style-type: none"> <li>Physical body</li> <li>Enjoyment of sex</li> <li>Different types of sexual behaviours</li> <li>Pregnancy</li> <li>Safe use of social media and communication technology</li> <li>Different types of relationships</li> <li>Boundaries in different relationships</li> <li>Maintaining safety in relationships</li> <li>Interpersonal skills in different relationships</li> <li>Interpreting social cues</li> <li>Appropriate and inappropriate behaviours in different situations</li> <li>Safe sex and sexual health</li> <li>Sexuality</li> <li>Consequences of own behaviours</li> <li>Sensory issues relating to sex</li> <li>Managing their own emotions</li> </ul>
Adaptations	<ul style="list-style-type: none"> <li>Therapeutic relationship</li> <li>Adapt to cognitive abilities</li> <li>Routine and planning of sessions</li> <li>Session boundaries</li> <li>Adapt communication</li> <li>Make abstract concepts concrete</li> <li>Visual aids</li> <li>Objects</li> <li>Videos / DVD</li> <li>Social Stories and scenarios</li> </ul>



Role-play  
Use published resources  
Group interventions  
Liaise with person's system

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### **3.2.R2Q development**

The codes arising from the thematic analysis of R1Q were generated into statements and worded similarly to panellists' data extracts, as recommended by Hasson, Keeney and McKenna (2000). The extensive list of 'topics' (see Appendix L) recommended by panellists, was not included in R2Q to minimise its size, and to focus R2Q on the research question concerning associated adaptations, rather than content. In total, 109 statements were included in R2Q (Appendix C) and presented within their corresponding categories; 'characteristics' (29 statements), 'assessment' (10 statements), and 'adaptations' (70 statements).

In the 'characteristics' section, panellists were asked to rate their agreement with each statement associated with the phrase; "This characteristic must be taken into account for all adults with ASD-LD when adapting sex education for this group". In the assessment section, panellists were asked to rate their agreement with each statement associated with the phrase, "This form of assessment must be conducted for all adults with ASD-LD prior to a sex education intervention". The 'characteristics' and 'assessment' statements were rated on five-point Likert scales (strongly agree, agree, neither agree nor disagree, disagree, or strongly disagree).

The aim of the 'adaptations' section was to discover which adaptations were particularly important for adults with ASD-LD, by comparing them to individuals with LD and ASD. Using a multiple-choice format with four options, panellists were

asked to select whether each adaptation was important for each of three clinical groups; ‘ASD-LD’, ‘LD only’ (without ASD), or ‘ASD only’ (without LD). The fourth option, ‘not important for any group’, was selected when the adaptation was believed to be unimportant for all three clinical groups.

R2Q also included 23 optional open-ended questions to further explore significant emerging themes from R1Q; including questions about the format of sex education and methods of assessment. Panellists were asked for examples of assessment methods only when they had rated ‘strongly agree’ or ‘agree’ for the statement associated with the assessment type. Other open-ended questions were included about specific characteristics and adaptations which required further clarity from R1Q. For example, ‘sensory sensitivities’ emerged as a characteristic but the influence of this on adaptations was unclear from R1Q. A section for further comments was included. R2Q took approximately 35 minutes to complete, and panellists were given 4-weeks to complete it.

### **3.3.R2Q analysis**

#### **3.3.1. Likert-scale ratings**

The Likert-scale ratings of the ‘assessment’ and ‘characteristics’ statements were analysed in the same way as R1Q (see methods section 2.7.1). Percentage calculations were conducted on the overall group Likert-scale ratings, to which consensus calculations were applied (Table 6).

#### **3.3.2. Multiple-choice ratings**

The multiple-choice ratings of the ‘adaptation’ statements were analysed using descriptive statistics and consensus calculations. A group total percentage for each

multiple-choice option ('ASD-LD', 'LD only', 'ASD only', and 'not important for any group') was calculated, and then initially allocated to the corresponding consensus category (see Table 6 in section 2.7.1.).

Similarly to previous research (Hackett et al., 2006), to demonstrate the level of importance of each adaptation for each clinical group (ASD-LD, LD only, and ASD only), the original consensus categories (Table 6) were then re-categorised as: 'essential' (indicated by 'high consensus'), 'desirable' (indicated by 'medium consensus'), 'additional' (indicated by 'low consensus') or 'not important' (indicated by 'no consensus'; Table 8). The fourth multiple choice option, "not important for any group", was not re-categorised, because it already stipulates that the adaptation is 'not important', so the original consensus categories (Table 6) remained applied to this option. For this option, consensus ratings above 50% suggested that panellists agreed the associated adaptation was not important for any clinical group.

Table 8: Importance categories for 'adaptations' statements

Importance categories	Percentage of panellists who rated the adaptation as 'important'	Definition of importance categories
Essential (indicated by high consensus)	≥80%	Adaptation likely to be important for all adults with ASD-LD/ LD/ ASD.
Desirable (indicated by medium consensus)	65-79%	Adaptation likely to be important for most adults with ASD-LD/ LD/ ASD.
Additional (indicated by low consensus)	50-64%	Adaptation likely to be important for some adults with ASD-LD/ LD/ ASD.
Not important (indicated by no consensus)	<50%	Adaptation not important for adults with ASD-LD/ LD/ ASD.

### 3.3.3. Qualitative responses

Qualitative data from R2Q was thematically analysed the same way as in R1Q (see methods section 2.7.2).

### 3.4.R2Q results

Overall, 105 out of 109 statements reached a consensus agreement among panellists.

For clarity, the results are organised into the three categories; ‘Characteristics’, ‘Assessment’, and ‘Adaptations’.

#### 3.4.1. Characteristics

Overall, consensus agreement was achieved for 28 out of 29 characteristic statements (Table 9). This suggests these characteristics, associated with adults with ASD-LD, should be taken into consideration when providing sex education. High consensus agreement was achieved for 15 characteristics, particularly those relating to interpersonal difficulties, concrete thinking style, and information processing deficits. A ‘low consensus’ agreement or ‘no consensus’ was achieved for characteristics associated with ‘mental capacity’, ‘sensory sensitivities’, and ‘memory and recall’.

Table 9: Consensus ratings of ‘characteristics’ of adults with ASD-LD.

	Agreement	Neutral	Disagreement
<b>High consensus</b>			
Difficulties generalising learning to different contexts	<b>100.00%</b> (n=15)	0.00% (n=0)	0.00% (n=0)
Difficulties understanding non-verbal communication (e.g. body language)	<b>93.34%</b> (n=14)	6.67% (n=1)	0.00% (n=0)
Difficulties developing relationships due to poor understanding of social rules	<b>93.33%</b> (n=14)	6.67% (n=1)	0.00% (n=0)
Difficulties with empathy and theory of mind	<b>93.33%</b> (n=14)	6.67% (n=1)	0.00% (n=0)
Difficulties understanding the impact of their behaviour on others	<b>93.34%</b> (n=14)	6.67% (n=1)	0.00% (n=0)
Information processing difficulties (e.g. may only process partial information)	<b>93.34%</b> (n=14)	0.00% (n=0)	6.67% (n=1)

Difficulties with understanding abstract and ambiguous concepts	<b>93.33%</b> (n=14)	6.67% (n=1)	0.00% (n=0)
Literal interpretations of language	<b>93.33%</b> (n=14)	6.67% (n=1)	0.00% (n=0)
Difficulties understanding social rules	<b>93.33%</b> (n=14)	6.67% (n=1)	0.00% (n=0)
Difficulties with knowing which behaviours are appropriate/ inappropriate	<b>86.67%</b> (n=13)	13.33% (n=1)	0.00% (n=0)
Difficulties understanding different relationships	<b>86.67%</b> (n=13)	6.67% (n=1)	6.67% (n=1)
Difficulties interpreting subtle social cues	<b>86.67%</b> (n=13)	13.33% (n=2)	0.00% (n=0)
Preference for structure and routine	<b>86.67%</b> (n=13)	13.33% (n=2)	0.00% (n=0)
Concrete thinking style	<b>80.00%</b> (n=12)	13.33% (n=2)	6.67% (n=1)
Difficulties understanding the consequences of their behaviours	<b>80.00%</b> (n=12)	13.33% (n=2)	6.67% (n=1)
<b>Medium consensus</b>			
Poor awareness of own emotions	<b>73.33%</b> (n=11)	13.33% (n=2)	13.34% (n=2)
Poor social skills	<b>73.34%</b> (n=11)	20.00% (n=3)	6.67% (n=1)
Emotional difficulties in relation to sex and relationships	<b>73.34%</b> (n=11)	13.33% (n=2)	13.33% (n=2)
Attention difficulties (e.g. easily distracted, poor attention span)	<b>73.33%</b> (n=11)	20.00% (n=3)	6.67% (n=1)
Difficulties with verbal communication	<b>66.67%</b> (n=10)	13.33% (n=2)	20.00% (n=3)
Inappropriate and challenging behaviours	<b>66.67%</b> (n=10)	13.33% (n=2)	20.00% (n=3)
Difficulties with problem solving	<b>66.67%</b> (n=10)	26.67% (n=4)	6.67% (n=1)
Difficulties dealing with rejection	<b>66.67%</b> (n=10)	26.67% (n=4)	6.67% (n=1)
<b>Low consensus</b>			
Limited mental capacity around issues of consent	<b>60.00%</b> (n=9)	26.67% (n=4)	13.34% (n=2)
Unusual sensory and sexual arousals	<b>60.00%</b> (n=9)	26.67% (n=4)	13.33% (n=2)
Difficulties with short term memory	<b>53.33%</b> (n=8)	26.67% (n=4)	20.00% (n=3)
Sensory sensitivities relating to sex/masturbation	<b>53.33%</b> (n=8)	40.00% (n=6)	6.67% (n=1)
Difficulties with recalling previously taught information	<b>53.34%</b> (n=8)	20.00% (n=3)	26.67% (n=4)
<b>No consensus</b>			
Limited mental capacity to engage in intimate relationships	46.67% (n=7)	33.33% (n=2)	20.00% (n=3)

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### 3.4.2. Assessment

Overall, all assessment statements (n=10) achieved a ‘medium’ to ‘high’ consensus agreement (Table 10), suggesting panellists agreed that these assessments should be conducted prior to sex education interventions.

Table 10: Consensus ratings of assessments required prior to sex education intervention for adults with ASD-LD.

	Agreement	Neutral	Disagreement
<b>High consensus</b>			
Assess their current knowledge about sex and relationships	<b>100%</b> (n=15)	0.00% (n=0)	0.00% (n=0)
Determine whether a person should be referred to a group or individual sex education intervention	<b>100%</b> (n=15)	0.00% (n=0)	0.00% (n=0)
Assess their communication abilities	<b>93.34%</b> (n=14)	6.67% (n=1)	0.00% (n=0)
Assess the potential emotional impact/ timing of the provision of sex education on the individual	<b>93.33%</b> (n=14)	6.67% (n=1)	0.00% (n=0)
Assess background history	<b>93.34%</b> (n=14)	0.00% (n=0)	6.67% (n=1)
Assessment of individual needs and preferences	<b>86.67%</b> (n=13)	13.33% (n=2)	0.00% (n=0)
A risk assessment must be conducted prior to sex education intervention	<b>80.00%</b> (n=12)	6.67% (n=1)	13.34% (n=2)
<b>Medium consensus</b>			
Assess their cognitive abilities	<b>73.33%</b> (n=11)	13.33% (n=2)	13.33% (n=2)
A capacity assessment must be conducted prior to sex education intervention	<b>66.67%</b> (n=10)	13.33% (n=2)	20.00% (n=3)
Assess for possible sensory sensitivities	<b>66.67%</b> (n=10)	20.00% (n=3)	13.34% (n=2)

Panellists recommended various methods of conducting assessment (Table 11). The most common method across all assessments types was to meet and interview the individual. Furthermore, panellists also recommended what factors determine an individual’s suitability to a group intervention, the most common included an ability

to socialise in a group setting, previous experiences of being in a group, and whether it is the individual's preference.

Table 11: Recommendations of methods for each 'assessment' type

<b>Assessment of needs and preferences of individual</b>	<b>Assessment of allocation to group or individual intervention</b>	<b>Risk assessment</b>
Meet with individual Previous professional involvement Sexual attitudes and knowledge assessment Capacity assessment Meet with carers/ family/ staff Gain consent from individual to gather information from system Use local standardised assessment protocol Individually tailored assessment	Individual preference Meet with individual Depends on what is available in service Risk assessment Historical information of individuals' ability to interact in a group Previous reports Consult with system (e.g. family, carers, professionals) Check individual has similar needs to group Part of referral process	Clinical interview with individual Liaise with system (e.g. family, carers, professionals) Take full risk history Assess for risk of abuse Assess for forensic risk Use formal risk assessment tools
<b>Assessment of cognitive abilities</b>	<b>Assessment of current knowledge</b>	<b>Assessment of mental capacity</b>
Meet with / interview individual Ability to process information during meeting Through assessment of knowledge Not a formal assessment of cognitive abilities	Interview individual Structured knowledge assessment Use published pictorial resources	Complete a mental capacity assessment Meet with individual Assess capacity throughout sessions Assess capacity using multiple communication methods
<b>Assessment of communication</b>	<b>Assessment of emotional impact and timing of sex education</b>	<b>Assessment of sensory sensitivities</b>
Interview individual Consult with speech and language therapists Informal assessment	Interview individual History taking Liaise with system Referral information Risk assessment	Meet with individual Liaise with system Formal sensory assessment

### 3.4.3. Adaptations

Overall, 67 out of 70 adaptations statements achieved a consensus agreement. The results are presented in subsections associated with the themes the adaptations were derived from, and some conceptually similar themes have been grouped together (e.g. cognitive and executive functioning abilities). To compare the level of importance (for ‘importance categories’ see Table 8 in section 3.3.2.) of each adaptation for each clinical group (adults with ‘ASD-LD’, ‘LD only’, or ‘ASD only’), the results are presented in tables. For clarity, the importance categories are formatted in bold when the associated adaptation was categorised as ‘additional’, ‘desirable’, or ‘essential’, or when there was a majority consensus agreement (>50%) that the adaptation was ‘not important for any group’. Statements which are labelled as ‘not important’ are those which achieved ‘no consensus’ (<50%), hence they are not formatted in bold. Finally, a summary of the adaptations interpreted as the most and least important for adults with ‘ASD-LD’ is presented.

The adaptations section of R2Q required panellists to select multiple-choice answers to rate the importance of each adaptation for each clinical group. However, two panellists (Panellist 3 and Panellist 21) only rated the importance of adaptations for adults with ‘ASD-LD’, except on one occasion a statement was rated important for adults with ‘LD only’. This was considered a systematic error, as considering these panellists rated the adaptations as important for adults with ‘ASD-LD’, it is likely they would have believed at least some of these adaptations were also important for adults with ‘LD only’ or ‘ASD only’. Therefore, these two panellists’ responses were removed from the final analysis for the ‘adaptations’ ratings only, to ensure more accurate comparison could be made between the three clinical groups.



### a) Adaptations for cognitive and executive functioning abilities

There were 17 statements associated with adaptations to support cognitive and executive functioning abilities. Nine of these adaptations emerged as ‘essential’ for adults with ‘ASD-LD’, which primarily related to adaptations for memory, attention, and information processing (Table 12). Overall, cognitive and executive functioning adaptations emerged as particularly important for adults with ‘ASD-LD’ and ‘LD only’; whereas adaptations associated with reducing distractions emerged as particularly important (‘desirable’ or ‘essential’) for adults with ‘ASD only’.

Table 12: Importance ratings of cognitive and executive functioning adaptations

Theme	Statements	ASD-LD	LD only	ASD only	Not important for any group
Executive functioning	Deliver teaching in distraction free settings	<b>Essential</b> (92.31%, n=12)	<b>Desirable</b> (76.92%, n=10)	<b>Essential</b> (84.62%, n=11)	No consensus (0.0%, n=0)
Executive functioning	Break down information into chunks	<b>Essential</b> (92.31%, n=12)	<b>Desirable</b> (76.92%, n=10)	<b>Additional</b> (61.54%, n=8)	No consensus (0.0%, n=0)
Cognitive abilities	Build in revision of previous sessions to aid memory	<b>Essential</b> (92.31%, n=12)	<b>Desirable</b> (76.92%, n=10)	<b>Additional</b> (61.54%, n=8)	No consensus (0.0%, n=0)
Cognitive abilities	Use frequent repetition and rehearsal of content to aid memory	<b>Essential</b> (92.31%, n=12)	<b>Desirable</b> (76.92%, n=10)	Not important (38.46%, n=5)	No consensus (0.0%, n=0)
Executive functioning	Adapt number of sessions to individual needs	<b>Essential</b> (92.31%, n=12)	<b>Desirable</b> (69.23%, n=9)	<b>Desirable</b> (69.23%, n=9)	No consensus (7.69%, n=1)
Executive functioning	Adapt length of session to individual needs	<b>Essential</b> (92.31%, n=12)	<b>Desirable</b> (69.23%, n=9)	<b>Desirable</b> (69.23%, n=9)	No consensus (7.69%, n=1)

Cognitive abilities	Focus on one idea at a time	<b>Essential</b> (84.62%, n=11)	<b>Desirable</b> (76.92%, n=10)	<b>Desirable</b> (76.92%, n=10)	No consensus (0.0%, n=0)
Cognitive abilities	Adapt to individuals' attention and memory abilities	<b>Essential</b> (84.62%, n=11)	<b>Desirable</b> (76.92%, n=10)	<b>Additional</b> (61.54%, n=8)	No consensus (0.0%, n=0)
Cognitive abilities	Use repetition of material in different ways to aid memory	<b>Essential</b> (84.62%, n=11)	<b>Desirable</b> (76.92%, n=10)	Not important (46.15%, n=6)	No consensus (0.0%, n=0)
Cognitive abilities	Ask open-ended questions about previous session to check recall	<b>Desirable</b> (76.92%, n=10)	<b>Essential</b> (84.62%, n=11)	<b>Additional</b> (53.85%, n=7)	No consensus (0.0%, n=0)
Cognitive abilities	Use visual prompts aid recall of previously taught material	<b>Desirable</b> (76.92%, n=10)	<b>Desirable</b> (76.92%, n=10)	<b>Additional</b> (53.85%, n=7)	No consensus (0.0%, n=0)
Cognitive abilities	Run sessions at a slow pace	<b>Desirable</b> (76.92%, n=10)	<b>Desirable</b> (76.92%, n=10)	Not important (46.15%, n=6)	No consensus (7.69%, n=1)
Cognitive abilities	Use visual prompts to aid memory	<b>Desirable</b> (69.23%, n=9)	<b>Desirable</b> (76.92%, n=10)	<b>Additional</b> (61.54%, n=8)	No consensus (0.0%, n=0)
Cognitive abilities	Provide feedback to client on their learning	<b>Desirable</b> (76.92%, n=10)	<b>Desirable</b> (69.23%, n=9)	<b>Additional</b> (61.54%, n=8)	No consensus (15.38%, n=2)
Cognitive abilities	Use clear pictures with no distracting backgrounds to aid processing	<b>Desirable</b> (76.92%, n=10)	<b>Additional</b> (61.54%, n=8)	<b>Desirable</b> (76.92%, n=10)	No consensus (0.0%, n=0)
Cognitive abilities	Give summary sheet of session to individual to improve recall	<b>Additional</b> (61.54%, n=8)	Not important (46.15%, n=6)	Not important (46.15%, n=6)	No consensus (38.46%, n=5)
Cognitive abilities	Provide short sessions	<b>Additional</b> (53.85%, N=7)	<b>Additional</b> (53.85%, n=7)	Not important (23.08%, n=3)	No consensus (30.77%, n=4)

### b) Adaptations for communication, visual aids, and objects

There were 12 out of 14 statements associated with adapting communication or using visual aids and objects which emerged as ‘essential’ for adults with ‘ASD-LD’ (Table 13). Overall, communication adaptations and visual aids, particularly using pictorials, were rated as most important for adults with ‘ASD-LD’ and ‘LD only’. The use of consistent language was particularly important for adults with ‘ASD only’. Using ‘written information’ emerged as an ‘additional’ adaptation for adults with ‘ASD-LD’, and not important for adults with ‘LD only’ and ‘ASD only’.

Table 13: Importance ratings of communication adaptations, visual aids, and objects

Theme	Statements	ASD-LD	LD only	ASD only	Not important for any group
Communication	Check understanding before moving onto a new idea	<b>Essential</b> (92.31%, n=12)	<b>Essential</b> (84.62%, n=11)	<b>Additional</b> (61.54%, n=8)	No consensus (0.0%, n=0)
Communication	Make materials accessible to individual	<b>Essential</b> (92.31%, n=12)	<b>Desirable</b> (76.92%, n=10)	<b>Additional</b> (61.54%, n=8)	No consensus (0.0%, n=0)
Communication	Use clear and simple language	<b>Essential</b> (92.31%, n=12)	<b>Desirable</b> (76.92%, n=10)	<b>Additional</b> (61.54%, n=8)	No consensus (0.0%, n=0)
Visual aids	Use visual aids to support communication	<b>Essential</b> (92.31%, n=12)	<b>Desirable</b> (76.92%, n=10)	<b>Desirable</b> (69.23%, n=9)	No consensus (0.0%, n=0)
Visual aids	Use pictorial aids	<b>Essential</b> (92.31%, n=12)	<b>Desirable</b> (76.92%, n=10)	<b>Additional</b> (61.54%, n=8)	No consensus (0.0%, n=0)
Visual aids	Use pictures to teach anatomy	<b>Essential</b> (92.31%, n=12)	<b>Desirable</b> (69.23%, n=9)	<b>Additional</b> (53.85%, n=7)	No consensus (7.69%, n=1)
Communication	Adapt communication to individuals	<b>Essential</b> (84.62%, n=11)	<b>Essential</b> (84.62%, n=11)	<b>Additional</b> (61.54%, n=8)	No consensus (0.0%, n=0)

	own communication methods				n=0)
Communication	Use easy read materials	<b>Essential</b> (84.62%, n=11)	<b>Essential</b> (84.62%, n=11)	Not important (30.77%, n=4)	No consensus (0.0%, n=0)
Communication	Frequently check understanding	<b>Essential</b> (84.62%, n=11)	<b>Essential</b> (84.62%, n=11)	<b>Additional</b> (61.54%, n=8)	No consensus (0.0%, n=0)
Communication	Use multiple methods of communication	<b>Essential</b> (84.62%, n=11)	<b>Desirable</b> (76.92%, n=10)	<b>Additional</b> (61.54%, n=8)	No consensus (0.0%, n=0)
Objects	Use model penis to practice condom application / to demonstrate sexually transmitted infection transmission	<b>Essential</b> (84.62%, n=11)	<b>Desirable</b> (76.92%, n=10)	<b>Desirable</b> (69.23%, n=9)	No consensus (0.0%, n=0)
Communication	Use consistent language	<b>Essential</b> (84.62%, n=11)	<b>Additional</b> (53.85%, n=7)	<b>Desirable</b> (76.92%, n=10)	No consensus (0.0%, n=0)
Objects	Use objects to aid memory and learning	<b>Additional</b> (61.54%, n=8)	<b>Additional</b> (61.54%, n=8)	Not important (46.15%, n=6)	No consensus (23.08%, n=3)
Visual aids	Use written information	<b>Additional</b> (61.54%, n=8)	Not important (23.08%, n=3)	Not important (46.15%, n=6)	No consensus (30.77%, n=4)

### c) Making abstract concepts concrete

All six adaptations associated with making abstract concepts concrete, emerged as ‘essential’ for adults with ‘ASD only’ and were particularly important for this group compared to those with ‘ASD-LD’ and ‘LD only’. Adaptations to ‘use concrete examples of abstract ideas’ and ‘avoid abstract and jargon language’ were rated as ‘essential’ for all three clinical groups (Table 14).

Table 14: Importance ratings of making abstract concepts concrete

Theme	Statements	ASD-LD	LD only	ASD only	Not important for any group
Make abstract concepts concrete	Avoid abstract and jargon language	<b>Essential</b> (84.62%, n=11)	<b>Essential</b> (84.62%, n=11)	<b>Essential</b> (92.31%, n=12)	No consensus (0.0%, n=0)
Make abstract concepts concrete	Use concrete examples of abstract ideas	<b>Essential</b> (84.62%, n=11)	<b>Essential</b> (84.62%, n=11)	<b>Essential</b> (92.31%, n=12)	No consensus (0.0%, n=0)
Make abstract concepts concrete	Use literal and concrete language	<b>Desirable</b> (76.92%, n=10)	<b>Additional</b> (61.54%, n=8)	<b>Essential</b> (92.31%, n=12)	No consensus (0.0%, n=0)
Make abstract concepts concrete	Use tangible teaching aids to make abstract information concrete	<b>Desirable</b> (76.92%, n=10)	<b>Essential</b> (84.62%, n=11)	<b>Essential</b> (92.31%, n=12)	No consensus (0.0%, n=0)
Make abstract concepts concrete	Explicitly teach how to recognise social cues in different relationships	<b>Desirable</b> (76.92%, n=10)	<b>Desirable</b> (69.23%, n=9)	<b>Essential</b> (92.31%, n=12)	No consensus (0.0%, n=0)
Make abstract concepts concrete	Explicitly teach which behaviours are appropriate/inappropriate in different relationships	<b>Desirable</b> (76.92%, n=10)	<b>Desirable</b> (69.23%, n=9)	<b>Essential</b> (84.62%, n=11)	No consensus (0.0%, n=0)

In R2Q, panellists were asked to provide examples of how abstract social cues and appropriate and inappropriate behaviours could be taught in more concrete ways (Table 15).

Table 15: Examples of methods to teach abstract concepts in concrete ways.

Theme	Codes
Concretely teaching how to recognise social cues (e.g. facial expression, body language, tone of voice) in different relationships	Tailor teaching abstract concepts to individuals' needs Use pictorials to teach how to recognise facial expression and body language Role-play Use videos/DVDs Use film and television clips Have discussions about how to recognise different facial expressions and body language Social Stories and scenarios
Concretely teach appropriate / inappropriate behaviours in different relationships	Pictures Visual aids Drawings 'Circles of intimacy' concept with pictures Role-play Videos / DVDs Use film and television clips Teach how to recognise others' feelings by thinking about their own feelings in the same situation Use scenarios and social stories Have discussions Teach concrete rules about touching Use 'ticks and crosses' / 'yes and no' symbols Use consent cards Use speech bubbles for different peoples' thoughts

#### d) Videos and DVD

Using videos or DVDs emerged as 'essential' for reinforcing learning in adults with 'ASD-LD', compared to those with ASD or LD only. Using videos or DVDs, emerged as 'desirable' to enable objective learning across all three clinical groups, but were more important to normalise difficulties in those with ASD only (Table 16).

Table 16: Importance ratings of videos or DVD

Theme	Statements	ASD-LD	LD only	ASD only	Not important for any group
Videos / DVD	Use videos / DVD to reinforce learning	<b>Essential</b> (92.31%, n=12)	<b>Desirable</b> (76.92%, n=10)	<b>Desirable</b> (69.23%, n=9)	No consensus

Videos / DVD	Use videos / DVD to enable objective learning and discussion of appropriate behaviours	<b>Desirable</b> (69.23%, n=9)	<b>Desirable</b> (69.23%, n=9)	<b>Desirable</b> (69.23%, n=9)	(0.0%, n=0) No consensus (15.38%, n=2)
Videos / DVD	Use videos / DVD to normalise difficulties	<b>Additional</b> (61.54%, n=8)	<b>Additional</b> (61.54%, n=8)	<b>Desirable</b> (69.23%, n=9)	No consensus (15.38%, n=2)

### e) Social Stories and scenarios

Five out of the six adaptations associated with Social Stories and scenarios emerged as ‘essential’ for adults with ‘ASD-LD’, and were most important for this group (Table 17). Social Stories used to teach about social cues and situations were more important for adults with ‘ASD only’ (‘desirable’), compared to ‘LD only’ (‘additional’).

Table 17: Importance ratings of social stories and scenarios

Theme	Statements	ASD-LD	LD only	ASD only	Not important for any group
Social Stories and scenarios	Use scenarios and Social Stories to simplify complex social situations, and enable the individual to problem solve	<b>Essential</b> (92.31%, n=12)	<b>Desirable</b> (76.92%, n=10)	<b>Desirable</b> (69.23%, n=9)	No consensus (7.69%, n=1)
Social Stories and scenarios	Use Social Stories and scenarios to explain boundaries and how to keep safe	<b>Essential</b> (92.31%, n=12)	<b>Additional</b> (61.54%, n=8)	<b>Desirable</b> (69.23%, n=9)	No consensus (7.69%, n=1)
Social Stories and scenarios	Use Social Stories to aid memory and recall of taught information	<b>Essential</b> (92.31%, n=12)	<b>Additional</b> (53.85%, n=7)	<b>Additional</b> (53.85%, n=7)	No consensus (7.69%, n=1)

Social Stories and scenarios	Use Social Stories to help individuals manage their anxiety in social situations	<b>Essential</b> (92.31%, n=12)	<b>Additional</b> (53.85%, n=7)	<b>Desirable</b> (69.23%, n=9)	No consensus (7.69%, n=1)
Social Stories and scenarios	Use Social Stories	<b>Essential</b> (84.62%, n=11)	<b>Additional</b> (61.54%, n=8)	<b>Additional</b> (61.54%, n=8)	No consensus (7.69%, n=1)
Social Stories and scenarios	Use scenarios	<b>Desirable</b> (76.92%, n=10)	Not important (46.15%, n=6)	<b>Additional</b> (61.54%, n=8)	No consensus (7.69%, n=1)

#### f) Role-play

Most role-play adaptations emerged as ‘essential’ or ‘desirable’ for all three clinical groups (Table 18). Using role-play to teach about empathy and theory of mind appeared most important for people ‘ASD only’.

Table 18: Importance ratings of role-play

Theme	Statements	ASD-LD	LD only	ASD only	Not important for any group
Role-play	Use role-play	<b>Essential</b> (84.62%, n=11)	<b>Desirable</b> (76.92%, n=10)	<b>Desirable</b> (69.23%, n=9)	No consensus (0.0%, n=0)
Role-play	Use role-play to make learning more meaningful	<b>Desirable</b> (76.92%, n=10)	<b>Essential</b> (84.62%, n=11)	<b>Desirable</b> (69.23%, n=9)	No consensus (0.0%, n=0)
Role-play	Use role-play to practice scenarios	<b>Desirable</b> (76.92%, n=10)	<b>Desirable</b> (76.92%, n=10)	<b>Desirable</b> (69.23%, n=9)	No consensus (0.0%, n=0)
Role-play	Use role-play to teach about empathy and theory of mind	<b>Additional</b> (61.54%, n=8)	<b>Desirable</b> (69.23%, n=9)	<b>Essential</b> (84.62%, n=11)	No consensus (0.0%, n=0)



### g) Routine and planning of sessions

Adaptations associated with the routine and planning of sex education sessions emerged as ‘essential’ to ‘additional’ for adults with ‘ASD-LD’ (Table 19). Overall, these adaptations were rated as more important for adults with ‘ASD-LD’ and ‘ASD only’, compared to adults with ‘LD only’, particularly with regards to preparing them for session changes or endings.

Table 19: Importance ratings of the routine and planning of sessions

Theme	Statements	ASD-LD	LD only	ASD only	Not important for any group
Routine and planning of sessions	Develop clear aims for each individual	<b>Essential</b> (84.62%, n=11)	<b>Additional</b> (53.85%, n=7)	<b>Additional</b> (53.85%, n=7)	No consensus (0.0%, n=0)
Routine and planning of sessions	Prepare individual for session endings and changes to plans	<b>Essential</b> (84.62%, n=11)	<b>Additional</b> (53.85%, n=7)	<b>Essential</b> (84.62%, n=11)	No consensus (0.0%, n=0)
Routine and planning of sessions	Stick to same time and frequency of sessions	<b>Desirable</b> (69.23%, n=9)	<b>Additional</b> (53.85%, n=7)	<b>Desirable</b> (76.92%, n=10)	No consensus (7.69%, n=1)
Routine and planning of sessions	Provide a structured session plan at the beginning	<b>Additional</b> (61.54%, n=8)	Not important (38.46%, n=5)	<b>Desirable</b> (69.23%, n=9)	No consensus (7.69%, n=1)

### h) Boundaries and therapeutic relationship

Adaptations associated with employing boundaries in sessions emerged as ‘essential’ for adults with ‘ASD-LD’, and particularly important for this group, compared to those with LD or ASD only. (Table 20).

Table 20: Importance ratings of session boundaries and the therapeutic relationship

Theme	Statements	ASD-LD	LD only	ASD only	Not important for any group
Boundaries	Be clear on educator's role and boundaries (e.g. remind individuals that educator cannot be in sexual relationship with individual)	<b>Essential</b> (92.31%, n=12)	<b>Desirable</b> (76.92%, n=10)	<b>Desirable</b> (76.92%, n=10)	No consensus (0.0%, n=0)
Boundaries	Provide session rules	<b>Essential</b> (84.62%, n=11)	<b>Additional</b> (61.54%, n=8)	<b>Desirable</b> (69.23%, n=9)	No consensus (7.69%, n=1)
Therapeutic relationship	Normalise and create a safe space to enable discussion of sensitive topics	<b>Desirable</b> (76.92%, n=10)	<b>Essential</b> (84.62%, n=11)	<b>Desirable</b> (76.92%, n=10)	No consensus (0.0%, n=0)

As 'session rules' emerged as a theme in R1Q, in R2Q panellists were asked for examples. These primarily related to instilling concrete social boundaries within the session, and enabling the individual to feel in control, safe and trust the facilitator (examples in Appendix M).

#### i) **Published resources**

Using published resources flexibly with individuals were considered 'essential' for all three clinical groups. Using published resources appeared more important for adults with 'ASD-LD' and 'LD only', than adults with 'ASD only' (Table 21).

Table 21: Importance ratings of using published resources

Theme	Statements	ASD-LD	LD only	ASD only	Not important for any group
Published resources	Flexibly adapt existing published resources to the individual	<b>Essential</b> (92.31%, n=12)	<b>Essential</b> (84.62%, n=11)	<b>Essential</b> (84.62%, n=11)	No consensus (0.0%, n=0)
Published resources	Use published resources to guide intervention	<b>Desirable</b> (76.92%, n=10)	<b>Desirable</b> (69.23%, n=9)	<b>Additional</b> (61.54%, n=8)	No consensus (7.69%, n=1)

#### j) Working with the person's system

The four adaptations associated with 'working with the person's system' (family, carers, or professionals), emerged as 'essential' or 'desirable' for adults with 'ASD-LD' (Table 22). These adaptations emerged as most important for those with 'ASD-LD;' and 'LD only'. However, for all clinical groups, it emerged as 'essential' that professionals, carers and families are supported and educated to develop more positive attitudes towards sex and relationships for this group.

Table 22: Importance ratings of working with the person's system

Theme	Statements	ASD-LD	LD only	ASD only	Not important for any group
Working with the person's system	Educate and support professionals/carers/families to develop more positive attitudes towards sex and relationships for this group.	<b>Essential</b> (84.62%, n=11)	<b>Essential</b> (92.31%, n=12)	<b>Essential</b> (84.62%, n=11)	No consensus (0.0%, n=0)
Working with the person's system	Provide systemic consultation with professionals/ carers/ families	<b>Essential</b> (84.62%, n=11)	<b>Essential</b> (84.62%, n=11)	<b>Desirable</b> (69.23%, n=9)	No consensus (0.0%, n=0)

Working with the person's system	Involve professionals/carers/families in sex education intervention to enable generalisation of learning outside of sessions	<b>Essential</b> (84.62%, n=11)	<b>Essential</b> (84.62%, n=11)	<b>Desirable</b> (69.23%, n=9)	No consensus (7.69%, n=1)
Working with the person's system	Give summary sheet to carer/ family member to enable them to remind person of key messages	<b>Desirable</b> (76.92%, n=10)	<b>Desirable</b> (69.23%, n=9)	Not important (38.46%, n=5)	No consensus (15.38%, n=2)

Panellists provided examples of ways to work with an individual's system in the context of sex education (examples in Appendix N), including providing training, consultation, and support groups. Involving families and carers within the sessions or sharing strategies to encourage application of taught information was important, as long as consent from the individual was sought, "It is always helpful if the family/system around them are involved, but this can only be done if they are in agreement with this" (Panellist 4).

### **k) Group interventions**

Group interventions emerged as 'not important', 'additional', or 'desirable', for all three clinical groups, and thus less important adaptations than others (Table 23). A 'medium consensus' agreement (69.23%, n=9) emerged that "a mixed mainstream and LD/ ASD group to enhance learning" was 'not important for any group'.

Table 23: Importance ratings of group interventions

Theme	Statements	ASD-LD	LD only	ASD only	Not important for any group
Groups enable learning	Provide group discussion of 'real life' examples to aid problem solving	<b>Desirable</b> (76.92%, n= 10)	<b>Desirable</b> (69.23%, n= 9)	<b>Additional</b> (53.85%, n= 7)	No consensus (7.69%, n= 1)
Groups enable learning	Run group exercises to make learning meaningful	<b>Additional</b> (61.54%, n= 8)	<b>Desirable</b> (76.92%, n= 10)	<b>Desirable</b> (69.23%, n= 9)	No consensus (15.38%, n= 2)
Groups are normalising	Provide group discussions to normalise difficulties	<b>Additional</b> (61.54%, n= 8)	<b>Desirable</b> (76.92%, n= 10)	<b>Desirable</b> (69.23%, n= 9)	No consensus (7.69%, n= 1)
Size of group intervention	Assign a small number of people in a group	<b>Additional</b> (61.54%, n= 8)	<b>Additional</b> (61.54%, n= 8)	<b>Desirable</b> (69.23%, n= 9)	No consensus (15.38%, n= 2)
Groups enable assessment of social interaction	Group interventions enable observation of an individuals' social interaction	Not important (46.15%, n= 6)	<b>Additional</b> (53.85%, n= 7)	<b>Additional</b> (61.54%, n= 8)	No consensus (23.08%, n= 3)
Groups enable learning	Provide group interventions to reinforce learning in individual sessions	Not important (38.46%, n= 5)	Not important (46.15%, n= 6)	Not important (38.46%, n= 5)	No consensus (38.46%, n= 5)
Groups enable learning	Provide a mixed mainstream and LD/ ASD group to enhance learning	Not important (30.77%, n= 4)	Not important (30.77%, n= 4)	Not important (30.77%, n= 4)	<b>Medium consensus</b> (69.23%, n= 9)

Themes emerging from qualitative responses suggested group interventions are not suitable for all individuals, “For some people with ASD & LD groups may not be appropriate at all” (Panellist 16). However, the benefits of group interventions emerged as a theme, where groups can enable peer interaction, “To make new friends and interact with people similar to their age and ability” (Panellist 11), and the

development of social skills, “by practicing social skills in a safe setting” (Panellist 1).

### **1) Most and least important adaptations for adults with ASD-LD**

Out of the 70 adaptations statements, the four ‘essential’ adaptations with the highest ratings for adults with ‘ASD-LD’, which were also rated as ‘essential’ for adults with ‘ASD only’ and ‘LD only’, were interpreted as the ‘most important’ adaptations overall for adults with ‘ASD-LD’. The four adaptations with the lowest total ratings across all three clinical groups, were interpreted as the ‘least important’ adaptations for adults with ‘ASD-LD’ overall (Table 24).

Table 24: Most and least important adaptations for adults with ASD-LD

Most important adaptations for adults with ASD-LD	Least important adaptations for adults with ASD-LD
1. Avoid abstract and jargon language	1. Provide a mixed mainstream and LD/ ASD group to enhance learning
2. Use concrete examples of abstract ideas	2. Provide group interventions to reinforce learning in individual sessions
3. Educate and support professionals/ carers/ families to develop more positive attitudes towards sex and relationships for this group.	3. Group interventions enable observation of an individuals' social interaction
4. Flexibly adapt existing published resources to the individual	4. Use written information

### **3.5.R3Q development**

Most statements in R2Q (105 out of 109) achieved consensus, therefore in R3Q panellists were asked to clarify areas of consensus and divergence, and speculate on a small selection of variable results, associated with adults with ASD-LD. As the characteristics ‘mental capacity’, ‘sensory sensitivities’, and ‘memory and recall’ achieved low or no consensus in R2Q, these areas were explored in R3Q. Social Stories had emerged as more important for adults with ‘ASD-LD’ compared to adults

with ‘LD only’ and ‘ASD only’, therefore panellists were asked to speculate on this finding. Also, panellists were asked to rate their agreement with ‘most’ and ‘least’ important adaptations for adults with ASD-LD (Table 24).

Therefore, R3Q (Appendix D) was divided into six sections; ‘most and least important adaptations’, ‘sensory sensitivities’, ‘mental capacity’, ‘memory and recall’, ‘social stories’, and ‘group interventions’. R3Q included a selection of results tables, written interpretations of results, and 14 five-point Likert scales. The results tables presented in R3Q adopted the original consensus calculations (Table 6) as this was prior the re-categorisation into ‘importance categories’ (Table 8 in section 3.3.2.) for the adaptations statements. Panellists could also add further comments. R3Q took approximately 20 minutes to complete, and panellists were given three weeks to complete it.

### **3.6.R3Q analysis**

#### **3.6.1. Quantitative data**

Likert-scale ratings were analysed in the same way as R1Q (see methods section 2.7.1). Percentage calculations were conducted on the overall group Likert-scale ratings, to which consensus calculations were applied (see Table 6, in section 2.7.1).

#### **3.6.2. Qualitative data**

Qualitative data from R2Q was thematically analysed the same way as in R1Q (see methods section 2.7.2).

### 3.7.R3Q results

The results are presented in the six sections which R3Q was divided into.

#### 3.7.1. Panellists' agreement with the most and least important adaptations

A 'high consensus' agreement was achieved for the 'most important' adaptations (Table 25). The 'least important adaptations' achieved more inconsistent consensus ratings, but achieved mostly a 'low' to 'medium consensus' agreement (Table 26).

Table 25: Consensus ratings of the 'most' important adaptations for adults with ASD-LD

Most important adaptations for adults with ASD-LD	Agreement	Neutral	Disagreement
Avoid abstract and jargon language	<b>High consensus</b> (100%, n=14)	No consensus (0.00%, n=0)	No consensus (0.00%, n=0)
Use concrete examples of abstract ideas	<b>High consensus</b> (100%, n=14)	No consensus (0.00%, n=0)	No consensus (0.00%, n=0)
Educate and support professionals/carers/ families to develop more positive attitudes towards sex and relationships for this group	<b>High consensus</b> (100%, n=14)	No consensus (0.00%, n=0)	No consensus (0.00%, n=0)
Flexibly adapt existing published resources to the individual	<b>High consensus</b> (92.86%, n=13)	No consensus (7.14%, n=1)	No consensus (0.00%, n=0)

Table 26: Consensus ratings of the 'least' important adaptations for adults with ASD-LD

Least important adaptations for adults with LD with ASD	Agreement	Neutral	Disagreement
Provide a mixed mainstream and LD/ ASD group to enhance learning	<b>Medium consensus</b> (71.43%, n=10)	No consensus (7.14%, n=1)	No consensus (21.43%, n=3)



Provide group interventions to reinforce learning in individual sessions	<b>Low consensus</b> (50.00%, n=7)	No consensus (28.57%, n=4)	No consensus (21.43%, n=3)
Group interventions enable observation of an individuals' social interaction	<b>Low consensus</b> (57.14%, n=8)	No consensus (28.57%, n=4)	No consensus (14.29%, n=2)
Use written information	<b>Low consensus</b> (50.00%, n=7)	No consensus (21.43%, n=3)	No consensus (28.57%, n=4)

The thematic analysis revealed that written information may be helpful for some,

“Written information can be helpful, but again not appropriate for everyone”

(Panellist 21). It was believed that mixed mainstream and LD or ASD groups are not effective at meeting individuals’ needs; “the material may need to be pitched at different levels which would inevitably exclude half of the group” (Panellist 10).

Themes associated with ‘group interventions’ are presented in the following section.

### 3.7.2. Group interventions

A ‘medium consensus’ agreement was achieved that providing group interventions are not essential adaptations for adults with ASD-LD (Table 27).

Table 27: Consensus ratings about group interventions for adults with ASD-LD

	Agreement	Neutral	Disagreement
Providing group interventions are not essential adaptations for adults with ASD-LD	<b>Medium consensus</b> (78.57%, n=11)	No consensus (7.14%, n=1)	No consensus (14.29%, n=2)

The thematic analysis revealed themes associated with the benefits and pitfalls of group interventions. The benefits included that the individual can hear others’ experiences, “learn from others’ experiences and strategies through group discussion” (Panellist 6), and practice social skills, “provide opportunities to practice social skills

within a safe environment” (Panellist 1). However, some reported groups may only be helpful for some, “desirable and important but may not suit all” (Panellist 14).

The pitfalls included that groups may not meet all individuals’ needs, “people’s experiences tend to vary so widely and their difficulties can be completely different and so it is hard to make this work in a group setting” (Panellist 10), and an individualised approach is preferred, “group work has a valued role but bespoke interventions are of a highly value to the service user” (Panellist 21). Some suggested that groups may be overstimulating, “the increased environmental stimulation may hinder their ability to learn and explore their own experiences” (Panellist 12).

### 3.7.3. Sensory sensitivities

A ‘high consensus’ agreement was achieved for sensory sensitivities impacting sexual behaviour, and the importance of the need for adaptations (Table 28). These results are divergent from the R2Q findings which achieved a ‘low consensus’ agreement for sensory sensitivities being an important characteristic (see section 3.4.1). The R3Q findings suggest panellists changed their views and a higher consensus agreement was achieved.

Table 28: Consensus ratings of characteristics and adaptations associated with sensory sensitivities in adults with ASD-LD

	Agreement	Neutral	Disagreement
<b>High consensus</b>			
Adults with LD and ASD are more likely than others to experience sensory sensitivities.	<b>100.00%</b> (n=14)	0.00% (n=0)	0.00% (n=0)
Sensory sensitivities impact on sexual behaviour / intimate contact.	<b>85.71%</b> (n=12)	14.29% (n=2)	0.00% (n=0)
If sensory sensitivities are present it is important to adapt sex education for these individuals.	<b>92.86%,</b> (n=13)	7.14% (n=1)	0.00% (n=0)

The thematic analysis revealed examples of how sensory sensitivities (e.g. to smell, taste and touch) can impact sexual behaviour. This included that adults with ASD-LD may seek stimulation through socially inappropriate and risky behaviours, “Sensory sensitivity may make some people with ASD seek unusual sensations during masturbation which may be dangerous” (Panellist 16). Themes pertaining to adaptations for sensory sensitives also arose; “adaptations may be necessary if the sensory sensitivity is such that it is stopping the person from having or wanting physical contact” (Panellist 10), and, “we practice putting condoms on a plastic penis and we need to have the anti-bacteria lotion ready as most people don't like the feel or smell of condoms” (Panellist 1).

#### 3.7.4. Social Stories

Social Stories being more important for adults with ‘ASD-LD’ than adults with LD or ASD only, did not reach consensus. However, a ‘high consensus’ agreement was achieved for Social Stories being important for meeting the social, communication, and cognitive needs of adults with ASD-LD (Table 29).

Table 29: Consensus ratings of ‘Social Stories’ as adaptations for adults with ASD-LD

Social Stories	Agreement	Neutral	Disagreement
Social stories are particularly important for adults with ASD-LD, in comparison to adults with LD only and ASD only	No consensus (42.86%, n=6)	No consensus (35.71%, n=5)	No consensus (21.43%, n=3)
Social stories are particularly important for adults with ASD-LD, because they meet the combination of the social skill needs for people with ASD, and the communication and cognitive needs for people with LD.	<b>High consensus</b> (85.71%, n=12)	No consensus (14.29%, n=2)	No consensus (0.00%, n=0)

The thematic analysis reflected the varied ratings associated with Social Stories being more important for adults with ASD-LD. Some suggested Social Stories are important for all three clinical groups, “social stories are needed for all clients where appropriate” (Panellist 1), whereas others believed Social Stories are particularly important for adults with ASD-LD, “I think people see social stories as important, but more so for those with ASD and LD” (Panellist 4).

### **3.7.5. Memory and recall**

The thematic analysis revealed key themes relating to adaptations, including using revision and repetition in multiples formats, “repeating information in different way we can be confident information is retained” (Panellist 1), and using visuals to aid memory, “The methods often used and known to be effective would inevitably help with recall of information - such as repetition of material and providing visual materials” (Panellist 10). Also, some panellists said that memory adaptations are helpful, regardless of memory difficulties;

“I think that people who work with adults with LD are used to taking account of difficulties with memory, so would take this into account "automatically" rather than considering it as a "characteristic" to consider” (Panellist 16).

### **3.7.6. Mental capacity**

The thematic analysis revealed that mental capacity assessment can guide the focus of sex education, “It highlights the areas where the client needs further Psycho-sexual education” (Panellist 3), but that is not essential for all, “I don't think it MUST be done prior to sex Ed. Sometimes it is useful. Sometimes it may not be useful” (Panellist 15). Some panellists also stressed the importance of not presuming the

person does not have capacity, “In principle there is an assumption of capacity for our clients in all areas of their lives” (Panellist 6). Some panellists suggested focusing on teaching consent, “Capacity to understand issues relating to consent is clearly important in relation to adapting sex education” (Panellist 16), and that sex education can increase mental capacity, “they may have gained the information needed by the end of the group to gain capacity” (Panellist 1).

#### **4. Discussion**

This three-round Delphi study explored the views of experienced health and social care professionals, on 1) which specific characteristics of adults with ASD-LD should be taken into consideration when providing sex education, and 2) what adaptations should be made to facilitate the delivery of sex education for adults with ASD-LD. Overall, experts in the field produced rich data, had a lot to share on this topic, and agreed that adults with ASD-LD have specific characteristics which require adaptations to sex education. This reflects previous research which suggests individuals with ASD-LD have unique needs (Matson & Shoemaker, 2009), as evidenced by most adaptations emerging as ‘essential’ for adults with ASD-LD, compared to more varied ratings for adults with LD and ASD.

The findings have value and potential to be developed into resources. However, the current study’s focus on adults with ASD-LD’s unique characteristics, and associated assessment and sex education adaptations, will be discussed, including; communication needs, cognitive and executive functions, social impairments, and sensory needs. Finally, the study’s limitations, and clinical and research implications are presented.

#### **4.1. Communication needs**

Research suggests that individuals with ASD-LD have more impaired communication than individuals with ASD (Noens & van Berckelaer-Onnes, 2004). Consistent with this, the current findings that non-verbal and verbal communication difficulties are important characteristics to adapt sex education for achieved a medium to high consensus agreement. Hence, a large proportion of recommended adaptations associated with using multiple methods of communication emerged as ‘essential’ (e.g. simplified language, visual aids) for individuals with ASD-LD. This is reflective of the ASD and LD sex education literature, which found visual aids are important adaptations (Schaafsma et al., 2013).

#### **4.2. Cognitive and executive functions**

A high consensus agreement was achieved that adults with ASD-LD tend to process partial information, think in concrete ways, and have difficulties generalising their learning (van Lang et al., 2006). This is consistent with findings suggesting individuals with ASD-LD have a weaker central coherence than those with LD (van Lang et al., 2006). Thus, it is unsurprising that adaptations associated with making abstract concepts concrete, reducing distractions, breaking information into smaller chunks, involving the person’s family to reinforce key messages, emerged as ‘desirable’ to ‘essential’. It was expected that ‘cognitive assessment’ to inform intervention adaptations achieved a medium consensus agreement, particularly as half of the panellists were psychologists, who have skills in cognitive assessment.

The limited evidence-base suggests working memory can be more impaired in individuals with ASD-LD, compared to those with LD (Barnard et al., 2008). This

may partly explain the current findings that suggests most adaptations for information processing, memory and attention (e.g. repetition in multiple formats), emerged as ‘essential’ for adults with ASD-LD. Considering adults with ASD-LD are believed to have attention and information processing difficulties, this may explain why group-programmes emerged as non-essential adaptations. Thus, it is unsurprising that assessment of group-intervention suitability is required, as individuals with ASD-LDs may become more distracted by others and facilitators cannot tailor group-sessions to every individual’s needs (Tarnai & Wolfe, 2008). However, consistent with previous reports from individuals with ASD, group-programmes were also thought to normalise difficulties (Barnett & Maticka-Tyndale, 2015).

### **4.3. Social impairments**

Individuals with ASD are believed to have an impaired ‘theory of mind’, impacting their understanding of social rules and others’ perspectives (Baron-Cohen et al., 1985; Tullis & Zangrillo, 2013). Previous research found individuals with ASD-LD have more impaired social skills than those with LD or ASD (Wilkins & Matson, 2009). The current findings are consistent with this, where a medium to high consensus agreement was achieved for social impairments being associated with adults with ASD-LD. Thus, a considerable number of adaptations, associated with their social needs (e.g. concretely teaching appropriate behaviours and social cues in different relationships), were rated as ‘desirable’ to ‘essential’. Also, using session rules and boundaries emerged as ‘essential’ adaptations, which may enable the explicit teaching of appropriate behaviours within sex education sessions. Finally, reflective of previous literature, Social Stories emerged as ‘essential’ for adults with ASD-LD, as

they incorporate concrete, simplified, and visual information, enabling the rehearsal of social situations (Travers & Tincani, 2010).

#### **4.4. Sensory needs**

The limited evidence-base suggests individuals with ASD-LD have greater sensory sensitivities than individuals with LD only (Joosten & Bundy, 2010), which can cause sexual behaviours to be experienced as aversive (Hellemans et al., 2007). Also, the additional social and cognitive deficits may reduce their ability to navigate fulfilling their sensory needs in a socially appropriate way (Ballan, 2012). This was reflected in the current study's findings, where panellists achieved a high consensus agreement that individuals with ASD-LD are more likely than others to experience sensory sensitivities, which may negatively impact sexual contact (e.g. finding kissing aversive). Therefore, some panellists suggested this group may need support with fulfilling their sensory needs in a safe and social acceptable way.

#### **4.5. Topics**

It is unsurprising that all panellists agreed that assessment of knowledge and risk prior to intervention is essential, as it determines the topics to focus upon. Panellists recommended a variety of topics, including; the body, functions of sex, relationships and interpersonal skills, inappropriate behaviours and their consequences, understanding social cues and emotions, enjoyment of sex, safe use of social media and technology, safe sex, sexual health, sexuality, and sensory issues relating to sex. The current topics are partly reflective of those in previous LD research (Sullivan & Caterino, 2008), yet a greater emphasis was placed on social skills within the current



topics. This is consistent with previous findings that social impairments are greater in those with ASD-LD (Wilkins & Matson, 2009).

#### **4.6. Strengths and limitations**

The electronic Delphi methodology allowed for rich data to be gathered on group opinion on a sensitive and complex topic, in a resource efficient way. As expected with the iterative rounds of questionnaires, a small attrition rate of panellists occurred at each round. Despite this, the sample size retained throughout the study is considered adequate for achieving consensus (Powell, 2003). The panellists were from a variety of professions, many of whom had provided sex education to over twenty individuals, with a significant number of years of experience, adding to the credibility that panellists could be considered ‘experts’ in the field.

The representation of health and social care professions in the sample was disproportionate, where half were clinical psychologists. However, this may reflect the provision of services, as psychologists and nurses are likely to be providing more sex education than other professionals. As sex education is provided in special education needs schools, for those up to 25 years old (Department of Education & Department of Health, 2015), it would have been beneficial to have included education professionals. This area warrants further scrutiny as there is a paucity of research on the effects of school-based sex education (Barnett & Maticka-Tyndale, 2015).

#### **4.7. Clinical Implications**

This study revealed the importance of considering individuals with ASD-LD as a distinct group with unique needs (Matson & Shoemaker, 2009), for which sex education interventions should be adapted for. The findings can be translated into practice, where the adaptations recommended could be adopted with this client group in a variety of psychoeducational interventions. There are useful existing sex education resources for professionals to use with people with LD (e.g. McCarthy & Thompson, 2016), however, there is scope for disseminating the findings as professional guidelines for sex education interventions for adults with ASD-LD.

#### **4.8. Research Implications**

As this study was exploratory, further research in this area is needed. Given the high consensus for the adaptations for adults with ASD-LD, future research could focus on investigating whether these adaptations to sex education lead to increased knowledge and applied skills in this population, both in individual and group interventions. It would also be essential to investigate the views of individuals with ASD-LD on these adaptations. Further research on the impact of sensory sensitivities on this population's ability to engage with sexual behaviours is warranted, as it could be a potential barrier to intimate relationships.

#### **4.9. Conclusion**

Individuals with ASD and LD have a desire for intimate relationships, however these populations can be vulnerable and have difficulties with developing intimate relationships. The research literature suggests that those with ASD-LD have greater impairments and unique needs compared to than those with ASD and LD, and thus

require specific adaptations to sex education to meet their unique needs. This study aimed to explore what experienced health and social care professionals believed were the most important characteristics and sex education adaptations for adults with ASD-LD. Rich data was gathered and it was found that experts in the field agree on the important characteristics and sex education adaptations required to meet the needs of this population, and that these differ for individuals with ASD and LD. This suggests adults with ASD-LD are a distinct population with unique needs. The characteristics and adaptations were primarily associated with communication needs, cognitive and executive functions, social impairments and sensory needs. The findings have implications for professionals who provide sex education for adults with ASD-LD, and the development of professional guidelines. The findings also have formed a foundation for further research to be conducted in this area.

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**Section C: Appendices of Supporting Material**

## Appendix A: Quality Assessment Scoring

### Quality Scoring of Quantitative Studies

**“Total sum** = (number of “yes” \* 2) + (number of “partials” \* 1)

**Total possible sum** = 28 – (number of “N/A” \* 2)

**Summary score:** total sum / total possible sum”

(p14; Kmet et al., 2004).

### Quality Scoring of Qualitative Studies

**“Total sum** = (number of “yes” \* 2) + (number of “partials” \* 1)

**Total possible sum** = 20

**Summary score:** total sum / total possible sum”

(p20; Kmet et al., 2004).



## Appendix B: Round 1 Questionnaire (R1Q)

3/3/2017

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### Introduction

## Sex Education for Adults with Autistic Spectrum Disorder with Learning Disabilities

### WELCOME

This is **Round 1 Questionnaire** which consists of **only 5 questions**. Before you answer these questions there will be a **demographic questionnaire**.

Please **read** the following guidelines:

- 1) Please complete this questionnaire as soon as possible. It closes at **midday on 9th July 2016**.
- 2) Reminder emails will be sent **two weeks** and **one week** before the closing date.
- 3) Allow **25-35 minutes** to complete this questionnaire
- 4) You can **pause and resume** this questionnaire **until midday on 9th July 2016**.  
**If you would like to complete/add to the questionnaire at a later date:**
  - **Close the internet browser/web page**
  - (Smart/mobile phone users: you will need to press 'next' on the page where you wrote your last answer, and then close the browser)**
  - **Re-enter the questionnaire by clicking the link in the original email**
  - Your responses are **saved automatically**.
  - **Do not delete the email** with the link to this questionnaire
- 5) Answer as **honestly and fully** as you can.
- 6) Answer based on **your own** experience and knowledge, rather than as a representation of an organisation/group.
- 7) Base your answers on your work with **adults** with a combination of **Autistic Spectrum Disorder with Learning Disabilities**.
- 8) **'Sex education'** includes formal programmes and less formal support (e.g. advising on matters of sexual behaviour and relationships).
- 9) **Give examples** of your work in this area.  
**Do not** include any names or information that could identify any service users, professionals, or services.
- 10) This questionnaire is completed **anonymously**.  
Your answers will be included in the final study, unless you request otherwise.

**PLEASE NOTE:** An **error message** will display when there are **unanswered questions**. Please **scroll to the top of the page** to see the error message **in order to progress**.

3/3/2017

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**Any queries/lost the original email?** Please contact: [k.c.taylor241@canterbury.ac.uk](mailto:k.c.taylor241@canterbury.ac.uk)

Thank you,

**Kelly Asagba**

**Please tick to confirm you have read and agree to the guidelines.**

- I have read and agree to the guidelines

## **Demographics**

Please complete the following demographics fields.

Round 1 Questionnaire will follow on the next page

**1) Participant ID number** (see the survey **invitation email** for your allocated ID number)

*This is to enable you to answer the questionnaire anonymously.*

**2) What is your ethnic group?**

*Choose one option that best describes your ethnic group or background*

White

1. English/Welsh/Scottish/Northern Irish/British
2. Irish
3. Gypsy or Irish Traveller
4. Any other White background

Mixed / multiple ethnic groups

5. White and Black Caribbean
6. White and Black African
7. White and Asian
8. Any other Mixed/Multiple ethnic background

Asian/Asian British

9. Indian
10. Pakistani
11. Bangladeshi
12. Chinese
13. Any other Asian background

Black/ African/Caribbean/Black British

14. African
15. Caribbean
16. Any other Black/African/Caribbean background

Arab

17. Arab

Other

18. Any other ethnic group

**3) Area of United Kingdom in which you currently work:**

e.g. South East England (If outside UK put the country)

**4) Current professional role:****5) Current service/work setting:****6) If you carried out 'sex education' in a previous professional role, please state your previous role here:****7) How many years have you worked with adults with Autistic Spectrum Disorder with Learning Disabilities?****8) Approximately, how many adults with Autistic Spectrum Disorder with Learning Disabilities have you provided 'sex education' for?**

*Remember: this includes **formal programmes** and less formal support (e.g. advising on matters of sexual behaviour and relationships).*

**9) Within the area of 'sex education' for adults with Autism with Learning Disabilities, have you had a role in any of the following for at least 2 years?**

*Tick all that apply:*

- Training
- Producing policy
- Consultation with other professionals
- Supervision of other professionals
- Research
- Resource development
- None of the above

Click **next** for the **Round 1 Questionnaire**.

**[Round 1 Questionnaire](#)**

This is Round 1 Questionnaire, it consists of **only 5 questions**.  
Please answer as **honestly and fully** as you can.

**Please note: An error message will display when there are unanswered questions**

**Either**

**Scroll to the top of the page to see the error message in order to progress.**

**Or**

**If you would like to complete/add to the questionnaire at a later date**

- **Close** the internet browser/web page

**(Smart/mobile phone users: press 'next' on the page where you wrote your last answer and then close the browser)**

- Your responses are **saved automatically**

- **To re-enter** the questionnaire, **click the link** in the original email

- **Do not delete the email** with the link to this questionnaire

(If you do, contact [k.c.taylor241@canterbury.ac.uk](mailto:k.c.taylor241@canterbury.ac.uk))

- You can add to this questionnaire until the **closing date - midday 9th July 2016.**

**Q1.**

**a) Please rate your agreement with this statement:**

*"Sex education specifically for adults with autistic spectrum disorder with learning disabilities is important"*

Strongly disagree



Disagree



Neither agree nor disagree



Agree



Strongly agree

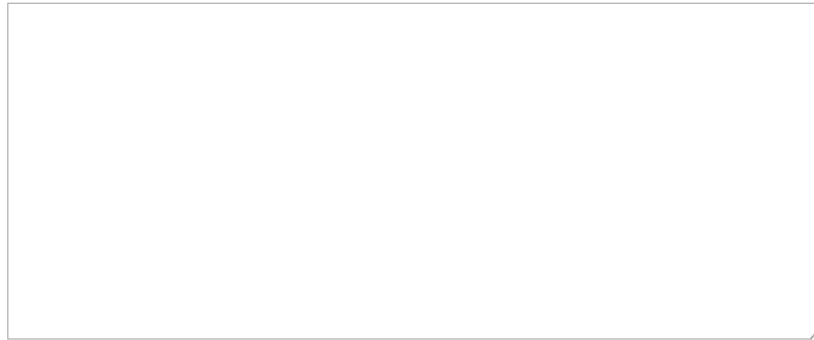


**b) Please explain why you have given this rating?**

**Q2. Which sex education topics are important for adults with a combination of Autistic Spectrum Disorder with Learning Disabilities?**

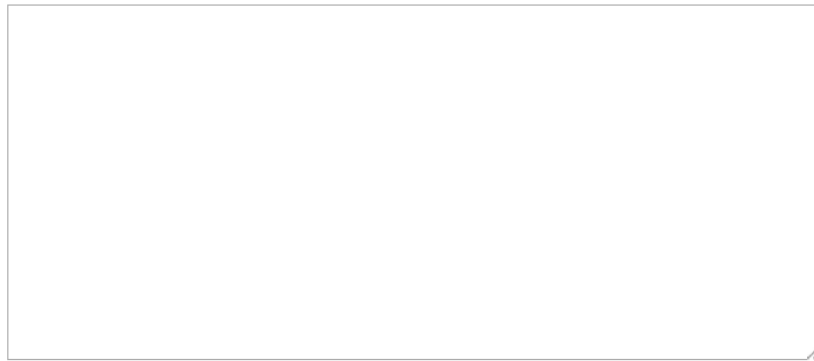
3/3/2017

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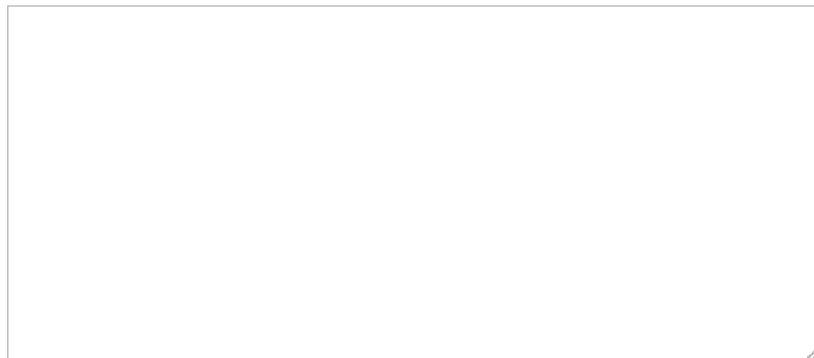
**Q3. What adaptations should be made to 'sex education' for adults with Autistic Spectrum Disorder with Learning Disabilities?**

*Please consider both content and delivery methods*

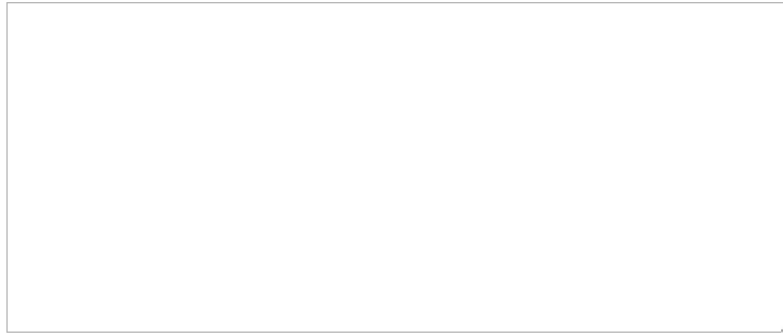


**Q4. How do these adaptations relate to the characteristics of adults with Autistic Spectrum Disorder with Learning Disabilities?**

*i.e. why these adaptations are important for this particular population*



**Q5. Any further comments?**

**PLEASE NOTE:**

An error message will display when there are **unanswered questions**.

- Please **scroll to the top of the page** to see the error message **in order to progress**

**OR**

- If you want to answer the questions at later stage, **follow the above instructions** (top of this page).

Thank you for completing the Round 1 Questionnaire.  
Please feel free to **check or add more** to your answers (press the '**back**' button).

**IMPORTANT:**

**Would you like to complete/add more to this questionnaire at a later date?**

- **Close the internet browser/webpage now** (do not click next - [including mobile/smart phone users](#))

- Your responses are **saved automatically**.

- Re-enter the questionnaire by **clicking the link in the original email**.

- You can add to this questionnaire **until the closing date - 9th July 2016 (at midday)**

- Lost the original email with the link to this questionnaire? Contact [k.c.taylor241@canterbury.ac.uk](mailto:k.c.taylor241@canterbury.ac.uk)

**OR**

**Have you completed the questionnaire and do not want to add more to your answers?**

- Press '**Next**'

- **Once you click next you will NOT be able to re-enter this questionnaire.**

**OR**

**Have you just arrived back at this page to add more to your answers?**

- Press '**Back**'

- Complete/add more to your answers

***Please ensure you have read the above options.***

*Once you click **next** you will **not** be able to re-enter the questionnaire, and your responses will be recorded.*

## Appendix C: Round 2 Questionnaire (R2Q)

Round 2

### Sex Education for Adults with Autistic Spectrum Disorder with Learning Disabilities

#### WELCOME

This is **Round 2 Questionnaire**.

The content in Round 2 has been developed based on themes derived from all participants answers in Round 1.

**Please read this carefully.**

This questionnaire is organised into **THREE main areas**:

1. **Characteristics** of adults with autism with learning disabilities
2. **Adaptations** to sex education intervention
3. **Assessment** prior to sex education intervention

Each area includes:

#### 1. Rating scales

- Please answer all of the rating scales
  - Please check each rating scale carefully, as their formats change throughout the questionnaire.
  - In the assessment section you may see a 'loading icon' as you answer the rating scales.
- Make sure the loading icon has disappeared before making each selection, as it may not select properly.

#### 2. Open-ended questions

- Please answer the open-ended questions, to elaborate on some specific areas if you can.
- Some open ended-questions will display based on your how you answer the rating scales.

Note:

All questions and rating scales are on one page.

Please read these guidelines:

<https://az1.qualtrics.com/ControlPanel/Ajax.php?action=GetSurveyPrintPreview>

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1) Please complete this questionnaire as soon as possible.  
It closes at **midday on Monday 10th October 2016**

2) Reminder emails will be sent approximately **two weeks** and **one week** before the closing date.

3) Allow **25-35 minutes** to complete this questionnaire

4) You can **pause and resume** this questionnaire **until** midday on Monday 10th October 2016.

5) **If you would like to complete/add to the questionnaire at a later date**

- **Close** the internet browser/web page

(Smart/mobile phone/tablet users: **first press 'next'**, on the page where you wrote your last answer, **then close** the browser)

- Re-enter the questionnaire by clicking the link in the original email

- Your responses are saved automatically.

- Do not delete the email with the link to this questionnaire

6) Base your answers on your own work with **adults** with a combination of **Autistic Spectrum Disorder with Learning Disabilities**.

7) **Do not** include any names or information that could identify any service users, professionals, or services.

8) This questionnaire is completed **anonymously**. Your answers will be included in the final study, unless you request otherwise.

9) Please answer **all** of the rating scales. Please answer open-ended questions where possible.

10) **Check** each rating scale carefully - their formats are different in each section.

**Error messages:**

- An **error message** will display when there are **unanswered questions**.

- Please **scroll to the top of the page** to see the highlighted questions/rating scales you have missed.

- **If you miss any rating scales**, only the **section** where you have missed a scale will **highlight** (not the specific answers).

- **If you miss any open-ended questions**, you may be prompted to answer them. If you wish to continue without answering, leave them blank.

**Any queries/lost the original email?**

Contact: k.c.taylor241@canterbury.ac.uk

Thank you,

**Kelly Asagba**

Please **tick** if you have **read and agree** to the guidelines

<https://az1.qualtrics.com/ControlPanel/Ajax.php?action=GetSurveyPrintPreview>

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I have read and agree to the guidelines

**Participant ID number**

(see the survey invitation email for your allocated ID number)

This is to enable you to answer the questionnaire anonymously.

**1. CHARACTERISTICS**

Participants suggested that the following **characteristics** of adults with autism with learning disabilities should be taken into consideration when adapting sex education.

**Statement:**

"This **characteristic must** be taken into consideration for **all** adults with autism with learning disabilities, when adapting sex education for this group"

**Tasks:**

a) Please **rate your level of agreement** with this statement for **each characteristic** listed below.

Note: Please check you have answered all of the rating scales.

b) Please answer any **open-ended questions** to elaborate further on some areas.

	Strongly Agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
<b>Interpersonal difficulties</b>					
Difficulties interpreting subtle social cues	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Difficulties understanding social rules	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Difficulties understanding different relationships	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Difficulties developing relationships due to poor understanding of social rules	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Poor social skills	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Difficulties with knowing which behaviours are appropriate/ inappropriate	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Difficulties with empathy and theory of mind	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
	Strongly Agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree

	Strongly Agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
Difficulties understanding the impact of their behaviour on others	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Difficulties dealing with rejection	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Difficulties understanding the consequences of their behaviours	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Inappropriate and challenging behaviours	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<b>Executive functioning difficulties</b>					
Information processing difficulties (e.g. may only process partial information)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Attention difficulties (e.g. easily distracted, poor attention span)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
	Strongly Agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
Difficulties with problem solving	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<b>Concrete thinking</b>					
Concrete thinking style	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Difficulties with understanding abstract and ambiguous concepts	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Literal interpretations of language	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Difficulties generalising learning to different contexts	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<b>Communication difficulties</b>					
Difficulties with verbal communication	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Difficulties understanding non-verbal communication (e.g. body language)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<b>Memory difficulties</b>					
Difficulties with short term memory	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Difficulties with recalling previously taught information	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<b>Emotional difficulties</b>					
Poor awareness of own emotions	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Emotional difficulties in relation to sex and relationships	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<b>Need for predictability</b>					
Preference for structure and routine	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<b>Mental capacity impairments</b>					
Limited mental capacity around issues of consent	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Limited mental capacity to engage in intimate relationships	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
	Strongly Agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree



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	Strongly Agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
<b>Sensory sensitivities</b>					
Unusual sensory and sexual arousals	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Sensory sensitivities relating to sex/masturbation	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

How might **sensory sensitivities** impact an individuals' ability to manage **intimate contact** in **interpersonal relationships**?  
(e.g. intimate contact could include touching, hugging, kissing, sexual intercourse, etc)

When supporting individuals with **sensory sensitivities relating to intimate contact**, in what ways does this affect **how** and **what** you teach in sex education?

## 2. ADAPTATIONS TO SEX EDUCATION

The following sex education adaptations for adults with autism with learning disabilities were suggested by participants.

**Aim:**

To find out which adaptations are particularly important, or need extra consideration, for those with a combination of autism with learning disabilities.

**Tasks:**

a) For **each adaptation**, please **SELECT ALL THAT APPLY**.

<https://az1.qualtrics.com/ControlPanel/Ajax.php?action=GetSurveyPrintPreview> 5/18

- **Important** for adults with **learning disabilities** (without autism)
  - **Important** for adults with **autism** (without learning disabilities)
  - **Particularly important / needs particular consideration** for adults with a combination of **autism with learning disabilities**
- OR:
- **Not important** (for those with learning disabilities, autism, or both)

b) Please answer any **open-ended questions** to elaborate further on some areas.

**Note:**

- Please check you have answered **all** of the ratings scales.
- **SELECT ALL THAT APPLY**

	Important for adults with learning disabilities	Important for adults with autism	Particularly important / needs particular consideration for adults with a combination of autism with learning disabilities	Not important
<b>Therapeutic relationship</b>				
Normalise and create a safe space to enable discussion of sensitive topics	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>Routine and planning of sessions</b>				
Stick to same time and frequency of sessions	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Provide a structured session plan at the beginning	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Develop clear aims for each individual	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Prepare individual for session endings and changes to plans	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Give summary sheet to carer/family member to enable them to remind person of key messages	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>Session boundaries</b>				
Be clear on educators role and boundaries (e.g. educator cannot be in sexual relationship with individual)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Provide session rules	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

List what you might include in sex education **session rules**?

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**2. Adaptations continued.....**

Note:  
Please select **all** that apply **OR** not important  
Please check you have answered **all** of the rating scales.

	Important for adults with learning disabilities	Important for adults with autism	Particularly important / needs particular consideration for adults with a combination of autism with learning disabilities	Not important
<b>Adapt to individual's memory abilities</b>				
Adapt to individuals attention and memory abilities	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Use frequent repetition and rehearsal of content to aid memory	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Use repetition of material in different ways to aid memory	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Build in revision of previous sessions to aid memory	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Use visual prompts to aid memory	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Use visual prompts aid recall of previously taught material	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Ask open ended questions about previous session to check recall	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Give summary sheet of session to individual to improve recall	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Provide feedback to client on their learning	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>Adapt to individual's executive functioning abilities</b>				
Deliver teaching in distraction free settings	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Use clear pictures with no distracting backgrounds to aid processing	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Break down information into chunks	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Focus on one idea at a time	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Run sessions at a slow pace	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

	Important for adults with learning disabilities	Important for adults with autism	Particularly important / needs particular consideration for adults with a combination of autism with learning disabilities	Not important
Adapt number of sessions to individual needs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Provide short sessions	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Adapt length of session to individual needs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

On average, what is the **maximum** and **minimum length of time** would you offer for **each session**?

**2. Adaptations continued.....**

Note:  
Please select **all** that apply **OR** not important  
Please check you have answered **all** of the rating scales.

	Important for adults with learning disabilities	Important for adults with autism	Particularly important / needs particular consideration for adults with a combination of autism with learning disabilities	Not important
<b>Adapt communication</b>				
Adapt communication to individuals own communication methods	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Use multiple methods of communication	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Make materials accessible to individual	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Use easy read materials	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Use clear and simple language	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

	Important for adults with learning disabilities	Important for adults with autism	Particularly important / needs particular consideration for adults with a combination of autism with learning disabilities	Not important
Use consistent language	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Frequently check understanding	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>Make abstract concepts concrete</b>				
Avoid abstract and jargon language	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Check understanding before moving onto a new idea	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Use literal and concrete language	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Use concrete examples of abstract ideas	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Use tangible teaching aids to make abstract information concrete	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Explicitly teach how to recognise social cues in different relationships	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Explicitly teach which behaviours are appropriate/inappropriate in different relationships	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

If any, give further **examples** of how you can **make abstract ideas concrete** when delivering sex education?

If any, what ways can you **concretely/explicitly teach** how to **recognise social cues in different relationships**?

If any, in what ways can you **concretely/explicitly teach** which **behaviours are inappropriate/appropriate in different relationships**?

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2. **Adaptations continued.....**  
 Note:  
 Please **select all that apply** OR **not important**  
 Please check you have answered **all** of the rating scales.

	Important for adults with learning disabilities	Important for adults with autism	Particularly important / needs particular consideration for adults with a combination of autism with learning disabilities	Not important
<b>Role play</b>				
Use role play	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Use role play to teach about empathy and theory of mind	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Use role play to make learning more meaningful	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Use role play to practice scenarios	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>Visual and audio teaching aids</b>				
Use visual aids to support communication	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Use pictorial aids	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Use pictures to teach anatomy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Use written information	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Use objects to aid memory and learning	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Use model penis to practice condom application / to demonstrate sexually transmitted infection transmission	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Use videos / DVD to reinforce learning	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Use videos / DVD to normalise difficulties	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Use videos / DVD to enable objective learning and discussion of appropriate behaviours	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

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	Important for adults with learning disabilities	Important for adults with autism	Particularly important / needs particular consideration for adults with a combination of autism with learning disabilities	Not important
<b>Social stories and scenarios</b>				
Use social stories	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Use scenarios (e.g. cartoon strips)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Use scenarios and social stories to simplify complex social situations, and enable the individual to problem solve	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Use social stories and scenarios to explain boundaries and how to keep safe	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Use social stories to aid memory and recall of taught information	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Use social stories to help individuals' manage their anxiety in social situations	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>Published resources</b>				
Use published resources to guide intervention	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Flexibly adapt existing published resources to the individual	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
If any, list examples of <b>published resources</b> you have found useful.				
<input type="text"/>				
<p>2. <b>Adaptations continued.....</b>  <b>Note:</b>                  Please select <b>all that apply</b> OR <b>not important</b>                  Please check you have answered <b>all</b> of the rating scales.</p>				

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	Important for adults with learning disabilities	Important for adults with autism	Particularly important / needs particular consideration for adults with a combination of autism with learning disabilities	Not important
<b>Group interventions</b>				
Provide group interventions to reinforce learning in individual sessions	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Provide group discussion of 'real life' examples to aid problem solving	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Provide a mixed mainstream and learning disabilities/autism group to enhance learning	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Run group exercises to make learning meaningful	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Provide group discussions to normalise difficulties	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Group interventions enable observation of an individuals' social interaction	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Assign a small number of people in a group	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
On average, what is the <b>maximum</b> and <b>minimum</b> number of adults with autism with learning disabilities you would assign to a <b>sex education group</b> ?				
<input type="text"/>				
<p>2. <b>Adaptations continued.....</b>  <b>Note:</b>                  Please select <b>all that apply</b> OR <b>not important</b>                  Please check you have answered <b>all</b> of the rating scales.</p>				

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	Important for adults with learning disabilities	Important for adults with autism	Particularly important / needs particular consideration for adults with a combination of autism with learning disabilities	Not important
<b>Liaise with person's system</b>				
Educate and support professionals/carers/families to develop more positive attitudes towards sex and relationships for this group.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Provide systemic consultation with professionals/carers/families	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Involve professionals/carers/families in sex education intervention to enable generalisation of learning outside of sessions	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

If any, what ways have you involved families/carers/professionals in sex education to enable the individual to generalise their learnt knowledge to practice?

If any, what other ways can you involve families/carers/professionals in the delivery of sex education?

### 3. ASSESSMENT

Many participants identified that different assessments prior to sex education are important.

**Statement:**

This form of assessment must be conducted for all adults with autism with learning disabilities prior to a sex education intervention.

**Task:**

- a) Please rate your level of agreement with the statement for each form of assessment  
 - Let the 'loading' icon disappear before making each selection, as they may not select properly.
- b) Please answer any open-ended questions that display.  
 - These additional questions will appear when selecting 'strongly agree' or 'agree' for each form of assessment.  
 - Answer based on your work with adults with BOTH autism with learning disabilities.

	Strongly Agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
<b>Assessment of individual needs and preferences</b>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Determine whether a person should be referred to a group or individual sex education intervention	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Assess background history	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Assess their cognitive abilities	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Assess their communication abilities	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Assess their current knowledge about sex and relationships	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Assess for possible sensory sensitivities	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Assess the potential emotional impact/timing of the provision of sex education on the individual	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
A risk assessment must be conducted prior to sex education intervention	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
A capacity assessment must be conducted prior to sex education intervention	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

If any, what other forms of assessment would you consider prior to sex education intervention?

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If any, **what methods** have you used to assess **individual needs and preferences** prior to sex education intervention?

If any, **what methods** have you used to **assess** whether to provide an **individual or group** sex education intervention?

If any, **what factors** would suggest a person could **benefit from a group intervention**?

If any, **what assessment methods** have you used to assess an individual's **cognitive abilities** prior to sex education intervention?

If any, **what methods** have you used to assess an individual's **communication abilities** prior to sex education intervention?

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If any, **what methods** have you used to **assess** an individual's **current knowledge** around sex and relationships?

If any, are there any **existing/published assessment resources** that you have found helpful in informing the provision of sex education intervention for this group?

If any, **what methods** have you used to **assess** an individual's **sensory sensitivities** prior to sex education intervention?

If any, **what methods** have you used to **assess** for the **potential emotional impact and/or the right timing** of sex education intervention for an individual?

*Many participants suggested that 'risks to self' (e.g. abuse/exploitation) and 'risks to others' (e.g. risk of harming others/being abusive to others) were an important rationale for sex education.*

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If any, what methods have you used to **assess for risk** (to self and/or others) prior to sex education intervention.

Some participants suggested that '**mental capacity**' was an area of difficulty for adults with autism with learning disabilities.

xi) If any, what what methods have you used to **assess the mental capacity** of an individual prior to sex education intervention.

Any further comments?

**Error messages**

- An **error message** will display when there are **unanswered questions**.
- Please **scroll to the top of the page** to see the error message **in order to progress**.

**Rating scales:**

- **If you miss any**, only the **section** where you have missed a scale will **highlight** (not the specific answers). Please check you have answered all of them.

**Open-ended questions:**

- If you miss any, the question will **highlight** and you will be prompted to answer. However, if you wish to continue without answering, leave them blank.

Thank you for completing the Round 2 Questionnaire.  
Please feel free to **check or add more** to your answers (press the '**back**' button).

**IMPORTANT:**

**Would you like to complete/add more to this questionnaire at a later date?**

- **close the internet browser/webpage now** (do not click next - including mobile/smart phone users)
- Your responses are **saved automatically**.
- Re-enter the questionnaire by **clicking the link in the original email**.
- You can add to this questionnaire **until the closing date** - at **midday on Monday 10th October 2016**.
- If you have **lost** the original email with the link to this questionnaire - **contact me** at [k.c.taylor241@canterbury.ac.uk](mailto:k.c.taylor241@canterbury.ac.uk)

**OR**

**Have you completed the questionnaire and do not want to add more to your answers?**

- Press '**Next**'
- **Once you click 'next'** you will **NOT be able to re-enter** this questionnaire.

**OR**

**Have you just arrived back at this page to add more to your answers?**

- Press '**Back**'
- Complete/add more to your answers

**Please ensure you have read the above options.**  
Once you click **next** you will **not** be able to re-enter the questionnaire, and your responses will be recorded.

## Appendix D: Round 3 Questionnaire (R3Q)

Default Question Block

### Sex Education for Adults with Autistic Spectrum Disorder with Learning Disabilities

WELCOME

#### This is Round 3 Questionnaire

Fifteen participants completed Round 2 Questionnaire.

In Round 2 questionnaire, a high level of consensus was gained across participants for the majority of the statements rated.

Therefore, instead of participants re-rating all of the statements from Round 2, Round 3 inquires further into a few areas which need clarity. This is the **last questionnaire**.

#### **Round 3 contains: 6 questions**

##### **Each question involves:**

- Commenting on a small selection of findings from Round 2
- Rating your agreement with statements (compulsory) - with space to justify your answers.

Round 3 is different to the previous rounds, so **please read all the instructions carefully**.

#### Please read these guidelines:

- 1) Please complete this questionnaire as soon as possible.  
**It closes at 5pm on Friday 23rd December**
- 2) Reminder emails will be sent approximately **two weeks** and **one week** before the closing date.
- 3) Allow **15-25 minutes** to complete this questionnaire
- 4) You can **pause and resume** this questionnaire **until the closing date**.

If you would like to complete/add to the questionnaire at a later date:

- **Close the internet browser/web page** (Smart/mobile phone users, **first press 'next'**, on the page where you wrote your last answer, and **then close** the browser)
- **Re-enter the questionnaire** by clicking the link in the original email
- Your responses are saved automatically.
- **Do not delete the email with the link to this questionnaire**

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5) **Do not** include any names or information that could identify any service users, professionals, or services.

6) This questionnaire is completed **anonymously**. Your answers will be included in the final study, unless you request otherwise.

#### **NOTE:**

- An error message will display when there are unanswered questions.
- Please scroll to the top of the page to see the error message in order to progress.

#### **Any queries/lost the original email?**

Contact: k.c.taylor241@canterbury.ac.uk

Thank you,

**Kelly Asagba**

Please tick if you have read and agree to the guidelines

I have read and agree to the guidelines

#### **Participant ID number**

(see the survey invitation email for your allocated ID number)

This is to enable you to answer the questionnaire anonymously.

#### Introduction

Please read carefully before completing Round 3

#### Glossary:

LD = Learning disabilities  
 ASD = Autistic spectrum disorder  
 LD only = adults with learning disabilities without autistic spectrum disorder  
 ASD only = adults with autistic spectrum disorder without learning disabilities  
 LD with ASD = adults with a combination of learning disabilities and autistic spectrum disorder.  
 Consensus = where there is a majority agreement (above 50%) for a particular answer.

#### How the results in Round 2 are organised:

To recap, Round 2 questionnaire included three sections: **characteristics, adaptations, and assessment**.

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The results from the five agreement levels on the rating scales in the 'assessment' and 'characteristics' sections in Round 2 were collapsed into *three* groups:  
 - 'agreement' (strongly agree and agree),  
 - 'neutral' (neither agree nor disagree)  
 - 'disagreement' (disagree and strongly disagree).

For the 'adaptations' section in Round 2, participants selected whether each adaptation was *important* or not important for adults with LD with ASD, LD only, and ASD only.

**Consensus categories:**

The percentage of participants' ratings on all rating scales in Round 2 were categorised into four levels of consensus (see Table 1).

Table 1: Consensus categories

Consensus categories	Percentage of participant ratings
High consensus	80% or more
Medium consensus	65% - 79%
Low consensus	50% - 64%
No consensus*	less than 50%

\* The 'adaptations' statements with ratings under 50% are categorised as 'not important' rather than 'no consensus'.

In the tables presented throughout this questionnaire, the percentages presented in **bold** show where the **highest level of consensus** was achieved for each statement (unless no consensus was achieved).

If you have read the above, please begin Round 3 Questionnaire - press next

NB: each question is on a separate page

**Round 3 Questionnaire**

**1. Most and least important adaptations**

Based on all participants' ratings from Round 2, these were considered the most and least important adaptations for adults with **LD with ASD** (Table 2). These were also rated as most and least important adaptations for adults with LD only and ASD only.

Table 2: The most and least important adaptations for adults with LD with ASD

Most important adaptations for adults with LD with ASD	Least important adaptations for adults with LD with ASD
1. Avoid abstract and jargon language	1. Provide a mixed mainstream and learning disabilities/ autism group to

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2. Use concrete examples of abstract ideas	enhance learning
3. Educate and support professionals/carers/ families to develop more positive attitudes towards sex and relationships for this group	2. Provide group interventions to reinforce learning in individual sessions
4. Flexibly adapt existing published resources to the individual	3. Group interventions enable observation of an individuals' social interaction
	4. Use written information

**Task:**

Please **rate your level of agreement** with the the following statements:

a) This adaptation is one of the **most important** adaptations for adults with **LD with ASD**

	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
Avoid abstract and jargon language	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Use concrete examples of abstract ideas	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Educate and support professionals/carers/ families to develop more positive attitudes towards sex and relationships for this group	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Flexibly adapt existing published resources to the individual	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

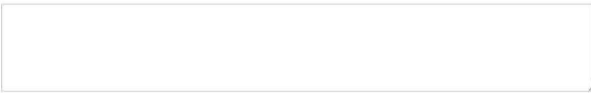
b) This adaptation is one of **least important** adaptations for adults with **LD with ASD**

	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
Provide a mixed mainstream and learning disabilities/ autism group to enhance learning	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Provide group interventions to reinforce learning in individual sessions	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Group interventions enable observation of an individuals' social interaction	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Use written information	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

c) Please **justify your ratings** / add any **comments** about the above results:

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### 2. Sensory sensitivities

A 'low consensus' *agreement* was achieved that sensory sensitivities are important 'characteristics' to consider when adapting sex education for adults with LD with ASD (Table 3).

Table 3. Characteristics associated with sensory sensitivities - overall participant ratings

	Agreement	Neutral	Disagreement
<b>Low consensus:</b>			
Unusual sensory and sexual arousals	60.00%	26.67%	13.33%
Sensory sensitivities relating to sex/masturbation	53.33%	40.00%	6.67%

Despite this, many participants provided written examples of how sensory sensitivities can present in adults with LD with ASD, and that these can impact their ability to manage intimate contact.

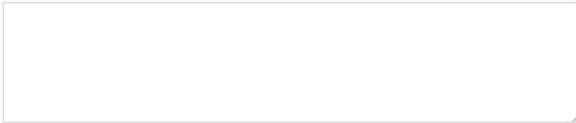
Also, many participants suggested that when an individual has sensory sensitivities, this can impact how sex education is adapted for these individuals. Alternatively, a couple of participants suggested that sensory sensitivities would not necessarily impact how sex education is adapted.

**Task:**

a) Please rate your agreement with the following statements:

	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
Adults with LD and ASD are more likely than others to experience sensory sensitivities	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Sensory sensitivities impact on sexual behaviour / intimate contact	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
If sensory sensitivities are present it is important to adapt sex education for these individuals	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

b) Please justify your ratings / add any comments about these results:



### 3. Mental capacity

A 'low consensus' *agreement* or 'no consensus' was achieved that 'limited mental capacity' is an important 'characteristic' to consider when adapting sex education for adults with LD with ASD (Table 4).

Table 4. Characteristics associated with mental capacity - overall participant ratings

	Agreement	Neutral	Disagreement
<b>Low consensus</b>			
Limited mental capacity around issues of consent	60.00%	26.67%	13.34%
<b>No consensus</b>			
Limited mental capacity to engage in intimate relationships	46.67%	33.33%	20.00%

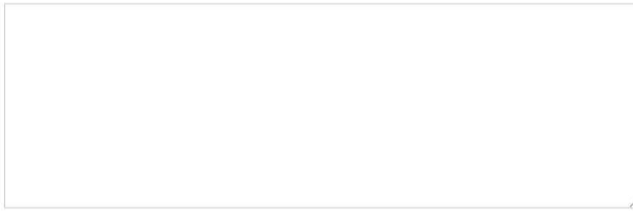
Despite this, a 'medium consensus' *agreement* was achieved that 'assessment' of 'mental capacity' should be conducted prior to sex education intervention (Table 5).

Table 5. Capacity assessment - overall participant ratings

	Agreement	Neutral	Disagreement
<b>Medium consensus</b>			
A capacity assessment must be conducted prior to sex education intervention	66.67%	13.33%	20.00%

**Question:**

Why do you think this is / how do you explain this result?



**4. Memory and recall**

A 'low consensus' *agreement* was achieved that difficulties with 'memory and recall' are important '**characteristics**' to consider when adapting sex education for adults with **LD with ASD** (Table 6).

*Table 6: Characteristics associated with mental capacity - overall participant ratings*

	Agreement	Neutral	Disagreement
<b>Low consensus</b>			
Difficulties with short term memory	<b>53.33%</b>	26.67%	20.00%
Difficulties with recalling previously taught information	<b>53.34%</b>	20.00%	26.67%

However, a 'medium' to 'high consensus' *agreement* was achieved that '**adaptations**' associated with memory and recall were **important** for adults with **LD with ASD** (Table 7).

*Table 7: Adaptations associated with memory and recall - overall participant ratings*

	Percentage of participants who rated the adaptation as <b>important</b> for adults with <b>LD with ASD</b>
<b>High consensus</b>	
Build in revision of previous sessions to aid memory	<b>92.31%</b>
Use frequent repetition and rehearsal of content to aid memory	<b>92.31%</b>
Adapt to individuals attention and memory abilities	<b>84.62%</b>
Use repetition of material in different ways to aid memory	<b>84.62%</b>
Use social stories to aid memory and recall of taught information	<b>92.31%</b>
<b>Medium consensus</b>	

Use visual prompts aid recall of previously taught material	<b>76.92%</b>
Ask open-ended questions about previous session to check recall	<b>76.92%</b>
Use visual prompts aid recall of previously taught material	<b>76.92%</b>
Give summary sheet to carer/ family member to enable them to remind person of key messages	<b>76.92%</b>
<b>Low consensus</b>	
Give summary sheet of session to individual to improve recall	<b>61.54%</b>
Use objects to aid memory and learning	<b>61.54%</b>

**Question:**

Why do you think this is / how do you explain this result?

**5) Social stories**

A 'high consensus' *agreement* was achieved that 'social stories' are important '**adaptations**' to sex education for adults with **LD with ASD** (Table 8).

However, only a 'low' to 'medium consensus' *agreement* was achieved that 'social stories' are important '**adaptations**' for adults with **ASD only** (without LD) and **LD only** (without ASD; Table 8)

*Table 8: Adaptations associated with social stories - overall participant ratings*

	Important for <b>LD with ASD</b>	Important for adults with <b>LD only</b>	Important for adults with <b>ASD only</b>	Not important for <b>any group</b>
Use scenarios and social stories to simplify complex social situations, and enable the individual to problem solve	<b>High consensus</b> 92.31%	<b>Medium consensus</b> 76.92%	<b>Medium consensus</b> 69.23%	No consensus 7.69%
Use social stories and scenarios to explain boundaries and how to keep safe	<b>High consensus</b> 92.31%	<b>Low consensus</b> 61.54%	<b>Medium consensus</b> 69.23%	No consensus 7.69%
Use social stories to aid memory and recall of taught information	<b>High consensus</b>	<b>Low consensus</b> 53.85%	<b>Low consensus</b> 53.85%	No consensus 7.69%

	92.31%			
Use social stories to help individuals manage their anxiety in social situations	<b>High consensus</b> 92.31%	<b>Low consensus</b> 53.85%	<b>Medium consensus</b> 69.23%	No consensus 7.69%
Use social stories	<b>High consensus</b> 84.62%	<b>Low consensus</b> 61.54%	<b>Low consensus</b> 61.54%	No consensus 7.69%

**Task:**

a) Please **rate** your level of agreement with the following statements:

	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
Social stories are <b>particularly important</b> for adults with <b>LD with ASD</b> in <b>comparison</b> to adults with LD <b>only</b> and ASD <b>only</b>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Social stories are <b>particularly important</b> for adults with <b>LD with ASD</b> because they meet the combination of the the social skill needs for people with ASD, and the communication and cognitive needs for people with LD.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

b) Do you have any **comments or alternative explanations** for the above results regarding social stories?

**6) Group interventions**

Overall, **group interventions** were rated as **less important** than the other '**adaptations**' to sex education for people with **LD with ASD** (Table 9).

*Table 9: Adaptations associated with group interventions - overall participant ratings*

	Percentage of participants who rated the adaptation as <b>important</b> for adults with <b>LD with ASD</b>
<b>Medium consensus</b>	
Provide group discussion of 'real life' examples to aid problem solving	<b>76.92%</b>
<b>Low consensus</b>	
Run group exercises to make learning meaningful	<b>61.54%</b>

<https://az1.qualtrics.com/ControlPanel/Ajax.php?action=GetSurveyPrintPreview>

9/11

Provide group discussions to normalise difficulties	<b>61.54%</b>
Assign a small number of people in a group	<b>61.54%</b>
<b>Not important*</b>	
Group interventions enable observation of an individuals' social interaction	46.15%
Provide group interventions to reinforce learning in individual sessions	38.46%
Provide a mixed mainstream and learning disabilities/ autism group to enhance learning	30.77%

\* For the 'adaptations' statements with ratings under 50% are categorised as '**not important**' rather than 'no consensus', as participants either selected that they were or were not important in Round 2.

**Task:**

a) Please **rate your agreement** with the following statement:

	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
Providing group interventions are <b>not essential</b> adaptations for adults with <b>LD with ASD</b>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

b) Please **justify your rating** / add **comment** on the the above results (i.e. why do you think this is?):

Thank you for completing the Round 3 Questionnaire.  
Please feel free to **check or add more** to your answers (press the '**back**' button).

**IMPORTANT:**

Would you like to **complete/add more** to this questionnaire **at a later date**?

- **Close the internet browser/webpage NOW (do not click next)**
- Your responses are **saved automatically**.
- Re-enter the questionnaire by **clicking the link in the original email**.
- You can add to this questionnaire **until the closing date - at 5pm on Friday 23rd December 2016**.
- If you have **lost** the original email with the link to this questionnaire - **contact me** at [k.c.taylor241@canterbury.ac.uk](mailto:k.c.taylor241@canterbury.ac.uk)

**OR**

<https://az1.qualtrics.com/ControlPanel/Ajax.php?action=GetSurveyPrintPreview>

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4/11/2017

Qualtrics Survey Software

**Have you completed the questionnaire and do not want to add more to your answers?**

- Press **Next**

- Once you click 'next' you will NOT be able to re-enter this questionnaire.

OR

**Have you just arrived back at this page to add more to your answers?**

- Press **Back**

- Complete/add more to your answers

**Please ensure you have read the above options.**

Once you click **next** you will **not** be able to re-enter the questionnaire, and your responses will be recorded.

## Appendix E: Study invitation email

### **Invitation Email:**

Dear all,

My name is Kelly Asagba, I am a Trainee Clinical Psychologist from the Salomons Centre for Applied Psychology (Canterbury Christ Church University). I am conducting my Major Research Project (thesis) on **how ‘sex education’ is adapted for adults with autism with learning disabilities.**

I am inviting professionals, who have experience in providing **sex education** for people with **autistic spectrum disorder with learning disabilities**, to take part in my **online survey**.

People with autistic spectrum disorder (ASD) and learning disabilities (LD) have the right and desire for intimate relationships. However, it is known that sexual behaviour can be ‘risky’, and those with ASD and LD are at greater risk of experiencing sexual abuse, mental health difficulties, and social isolation. Therefore, providing appropriate sex education and support is important to help reduce these risks. However, despite the high prevalence of individuals with comorbid ASD with LD, it is disappointing that the research on adapting sex education for this population is almost non-existent. In light of this, it is important that greater detail is sought on how sex education for people with LD with ASD is provided in practice.

### **Participants must:**

- Be a health or social care professional currently working in/with specialist Autism or Learning Disabilities services (this include pre-qualification professions, such as assistant psychologists and nursing assistants, as long as they meet the criteria)

### **AND**

- Have been involved in providing ‘sex education’ for an average of 2 or more adults who have autistic spectrum disorder with learning disabilities on average per year, for at least 2 years.

### **OR**

- Have a role in training and/or producing policy and/or supervision and/or consultation for other professionals and care staff, within the area of 'sex education' for adults with autistic spectrum disorder with learning disabilities, for at least 2 years.

### **OR**

- Be a health/ social care/ education professional not currently working in/with specialist Autism or Learning Disabilities services, but have had provided 'sex education' for a minimum of 10 adults with autistic spectrum disorder with learning disabilities, over their career.

### **‘Sex education’ definition:**

In this study, ‘sex education’ is considered as advising on matters of sexual behaviour and relationships, either through **formal programmes or less formalised interactions**, directly with adults with autism with learning disabilities.

**If you decide to take part:**

- You will be sent a study information sheet and consent form via email. You will be given the opportunity to contact me, the researcher, with any questions you may have.
- You will be sent three electronic questionnaire via email at separate stages. All rounds are anticipated to be completed within a 6-month period.
- Each questionnaire will take approximately 25-30 minutes to answer.
- You will be given the opportunity for a follow-up discussion with me, the researcher, and time for any questions to be answered.
- The study is anonymous and confidential, and has full ethical approval from Canterbury Christ Church University.

**Please pass this email onto others:**

I would be very grateful if you could pass on this study information to others who may be interested, as we aim to recruit up to 50 people.

There is a **flyer attached** that can be printed off and taken to conferences, displayed on notice boards, or handed to others.

**To participate / more information:**

Please contact me at [k.c.taylor241@canterbury.ac.uk](mailto:k.c.taylor241@canterbury.ac.uk)

Thank you for taking the time to read this email. I look forward to hearing from you.

Kind regards,

Kelly

**Kelly Asagba****Trainee Clinical Psychologist**

Salomons Centre for Applied Psychology  
Canterbury Christ Church University  
Broomhill Road  
Tunbridge Wells, Kent TN3 0TF

Please note that emails are not a secure source of communication and confidentiality cannot be assured. For sustainability reasons, please consider the need to print this email or attachments.

## Appendix F: Study information sheet

### Information Sheet

#### **Project Title: Sex education for adults with Autistic Spectrum Disorder with Learning Disabilities: A Delphi Study**

My Name is Kelly Asagba, and I am a Trainee Clinical Psychologist at the Salomon's Centre for Applied Psychology, Canterbury Christ Church University (CCCU). I would like to invite you to take part in this research study, funded by CCCU. Before you decide whether to take part, please read this information.

**Researchers:** Kelly Asagba (supervised by Professor Jan Burns and Dr Sophie Doswell).

#### **Purpose of the study:**

I am interested in understanding more about how sex education can be adapted for adults with a diagnosis of autism spectrum disorder (ASD) with learning disabilities (LD).

People with ASD and LD have the right and an expressed desire for intimate relationships. However, it is known that sexual behaviour can be 'risky', and those with ASD and LD can be at greater risk of abuse, mental health difficulties, or social isolation if not provided with appropriate sex education and support. There is a fairly large evidence-base on adapting sex education for individuals with LD, but in comparison it is fairly limited for individuals with ASD. However, despite the high prevalence of individuals with comorbid ASD and LD, it is disappointing that the research on adapting sex education for this population is almost non-existent. In light of this, it is important that greater detail is sought on how sex education for people with LD with ASD is provided in practice.

#### **Aim of the study:**

To gather an 'expert' consensus on how best to adapt sex education for adults with ASD with LD from those who have experience in this area. 'Expertise' is based on a level of experience in this area of work (see below, *'Am I eligible to take part?'*).

#### **Implications of the study:**

This study could provide more detailed information on how to best support adults with a diagnosis of ASD with LD with intimate relationships and sexual health issues. The findings could have implications for the provision of sex education for adults with ASD with LD, and could inform practice for psychologists, care workers, nurses, and other professionals involved in delivering sex education to this population. Importantly, the findings could provide guidance for, and lead to the development of, effectively adapted sex education for adults with ASD with LD. The findings could also provide a foundation for further research in this area.

#### **Am I eligible to take part?**

The approach taken in this study is the Delphi method. This involves recruiting people with a level of 'expertise' based on their experience in a particular area of work. This study considers an 'expert' to meet the following criteria:

- Be a health or social care professional currently working in/with specialist Autism or Learning Disabilities services (this include pre-qualification professions, such as assistant psychologists and nursing assistants, as long as they meet the criteria).



**AND**

- Have been involved in providing 'sex education' for an average of 2 or more adults who have autistic spectrum disorder with learning disabilities<sup>3</sup> on average per year, for at least 2 years.

**OR**

- Have a role in training and/or producing policy and/or supervision and/or consultation for other professionals and care staff within the area of sex education for adults with autistic spectrum disorder with learning disabilities, for at least 2 years.

**OR**

- Be a health or social care professional not currently working in/with specialist Autism or Learning Disabilities services, but have had provided 'sex education' for a minimum of 10 adults with autistic spectrum disorder with learning disabilities, over their career.

**'Sex education' definition:**

In this study, sex education is considered as **formal programmes or less formalised interactions**; when you have had direct contact with adults with autism with learning disabilities and have advised on matters of sexual behaviour and relationships.

**What will the study involve?**

- Via email, you will be asked to complete three electronic questionnaires. These will be sent at separate stages, as they are part of a circular process of questioning. All three rounds are anticipated to be completed within a 6 month period.
- Each round will take approximately 25-35 minutes to answer and will involve both written answers and rating scales.
- You will be given the opportunity for a follow-up discussion with me, the researcher, and time for any questions to be answered.

**Details of procedure:****Round 1**

You will be sent an email with an individual participant ID and an electronic link to the online Round 1 Questionnaire, which will also include a demographics questionnaire. Round 1 Questionnaire will include mainly open-ended questions, should take between 25-35 minutes to complete, and you will be asked to complete it within 4 weeks of being sent the link. You will be able to pause and add to the questionnaire at any time until the closing date. To allow for recruitment, it is anticipated this questionnaire will be sent in early June 2016.

**Round 2**

You will be sent an email with an electronic link to the online Round 2 Questionnaire approximately 3-4 weeks after the close of Round 1. The responses from Round 1 will be analysed to develop the Round 2 Questionnaire. The main themes and ideas from all participants' responses in Round 1 will be combined to produce a list of statements, to develop the Round 2 Questionnaire. You will be asked to rate your level of agreement with these statements. No identifiable information will be linked with the responses, and participants will remain anonymous to one another. The Round 2 questionnaire should take less time to complete than Round 1, as it will primarily include rating scales, but it is likely to also contain a few additional open-ended questions. Round 2 should take no more than 25-35 minutes to complete, and

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<sup>3</sup> Adults with autistic spectrum disorder whose intellectual functioning and impaired adaptive functioning is significantly impaired (BPS, 2000)

you will be asked to complete it within 4 weeks of being sent the link. You will be able to pause and resume the questionnaire at any time until the closing date.

### **Round 3**

You will be sent an email with an electronic link to the online Round 3 Questionnaire approximately 2-3 weeks after the close of Round 2. The responses from Round 2 will be analysed to develop the Round 3 Questionnaire. The round 3 Questionnaire will present participants combined agreement ratings from Round 2. You will be asked to review and re-rate the statements, and provide comments or feedback in response to participants' overall ratings. Also, if open-ended questions were included in Round 2, you will be asked to rate your level of agreement with statements derived from all participants' responses. No identifiable information will be linked with the responses, and participants will remain anonymous to one another. Round 3 should take no more than 25-35 minutes to complete, and you will be asked to complete it within 4 weeks of being sent the link. You will be able to pause and resume the questionnaire at any time until the closing date.

By Round 3 it is expected that a consensus will be gained on 'sex education for adults with ASD with LD'.

### **Consensus report and debrief**

Once data from Round 3 has been analysed, all participants will be sent a debrief and a consensus report, detailing the level of consensus amongst all participants on how sex education should be provided to adults with autistic spectrum disorder with learning disabilities. A discussion with the researcher via telephone will be offered, if required.

### **Is the study confidential?**

Yes, all information which is collected during the course of the research will be kept strictly confidential. You will remain anonymous throughout the study to prevent your responses from being identifiable to others. No names or identifying features will be used in the study, instead you will be allocated a participant ID number. Your responses to the questionnaires will be shared with other participants, but your name and identifying information will not be attached to your responses nor shared with other participants. You will also be asked to refrain from detailing any information on any service users, professionals or services.

Some direct quotes from the questionnaire may be used in the study write-up (thesis and journal article) however, quotes will not be linked with any identifying features or names. You have the right to check the accuracy of your responses. You are free to withdraw from the study at any time without explanation. If you withdraw part of the way through the study, your responses up to this point may be used in the study, unless you request otherwise.

### **Who has reviewed the study?**

This study has been reviewed and given full ethical approval and favourable opinion by the Salomon's Centre for Applied Psychology (CCCU) Research Ethics Committee.

### **What will happen to the results of the research study?**

This research study will be written up as my Major Research Project (thesis) towards my Doctorate in Clinical Psychology, and will be submitted for publication to a journal. It will also be uploaded to the CCCU research repository. I will also provide all participants who have taken part in the study with a summary of the findings.

**How do I take part?**

If you would like to take part, have read and understood this information and you meet the above inclusion criteria, please read, insert your name, and email me the consent form. I will email you to let you know when I have received it.

**What do I do if I have any concerns or complaints about the study?**

If you have any concerns about any aspect of this study, you can speak to me (see details below) and I will do my best to answer your questions. If you remain unhappy and wish to complain formally, you can contact Professor Paul Camic, Research Director, at Canterbury Christ Church University via email: [paul.camic@canterbury.ac.uk](mailto:paul.camic@canterbury.ac.uk), or telephone: 03330 117 114.

**Further information and contact details:**

If you would like to speak to me and find out more about the study, or have any questions:

Email: [k.c.taylor241@canterbury.ac.uk](mailto:k.c.taylor241@canterbury.ac.uk)

Mobile phone: 07738377660

Yours sincerely,

**Kelly Asagba**

Trainee Clinical Psychologist

Salomon's (CCCU) Doctorate in Clinical Psychology Programme

## Appendix G - Study advertisement flyer



**Let's talk about... 'sex education'**  
**Are you interested in talking about how you adapt sex education  
 for people with Autism with Learning Disabilities?**

**Please consider participating in this online study**

Participants must:

- Be a **health or social care professional** currently working in/with specialist **Autism or Learning Disabilities services** (this include pre-qualification professions, such as assistant psychologists and nursing assistants, as long as they meet the criteria).

**AND**

- Have been involved in providing '**sex education**' for an average of **2 or more adults** who have autistic spectrum disorder with learning disabilities **on average per year, for at least 2 years.**

**OR**

- Have a role in **training and/or producing policy and/or supervision and/or consultation** for other professionals and care staff within the area of '**sex education**' for adults with autistic spectrum disorder with learning disabilities, for **at least 2 years.**

**OR**

- **Not currently working in/with specialist Autism or Learning Disabilities services,** but have had provided '**sex education**' for a **minimum of 10 adults** with autistic spectrum disorder with learning disabilities, **over their career.**

**'Sex education' = formal programmes or less formalised interactions**  
*e.g. directly advising on matters of sexual behaviour and relationships*

Participation involves completing **3 electronic questionnaires**, sent via email at separate stages, as they are part of a circular process of questioning. Each questionnaire takes approximately 25-35 minutes to complete, over approximately a 6 month period.

To participate, or for more information, please contact Kelly Asagba at

[k.c.taylor241@canterbury.ac.uk](mailto:k.c.taylor241@canterbury.ac.uk)

Thank you!

**Kelly Asagba**

Trainee Clinical Psychologist, Salomon's (CCCU) Doctorate in Clinical Psychology Programme

**Appendix H - Letter of full ethical approval from university ethics committee.**

This has been removed from the electronic copy

## Appendix I: Consent Form

**Project Title: Sex education for adults with Autistic Spectrum Disorder with Learning Disabilities: A Delphi Study**

**Name of Researcher:** Kelly Asagba

To take part in this study, please **read** and **initial** the following statements, and **write your name below**.

	Please initial each box.
1. I have read and understood the information sheet for this research study.	
2. Based on the information provided, I have had the opportunity to ask the researcher questions and have been provided with acceptable answers.	
3. I understand that I will be sent three rounds of questionnaires electronically, via email, and agreed to be contacted via email from the researcher. This may also involve some verbal communication if required.	
4. I understand I am free to withdraw from the research at any time without providing a reason, and that if I withdraw part of the way through the study, my responses will be used in the study unless I request otherwise. I can do this via email or phone.	
5. I understand that my data will remain confidential and anonymous in line with the Data Protection Act.	
6. I understand that parts of my questionnaire responses may be quoted verbatim in the questionnaires and research report, and if this occurs, I will remain anonymous.	
7. I understand that my responses will be seen by other participants, but my name and other identifiable information will <u>not</u> be attached to these responses. I understand that I will remain anonymous to other participants.	
8. I understand that I must not write down any identifiable information of any service users, other professionals or services.	
9. I understand that all my data will be anonymised and stored electronically using encryption.	
10. I agree to take part in this research study.	

By emailing this completed form back to the researcher, you are providing consent to take part in the study.

Name of Participant \_\_\_\_\_ Date \_\_\_\_\_

Please **complete, save and email** this form to Kelly Asagba: [k.c.taylor241@canterbury.ac.uk](mailto:k.c.taylor241@canterbury.ac.uk)

Thank you

## Appendix J: Participant feedback letter



### Study: Sex education for adults with Autistic Spectrum Disorder and Learning Disabilities

Dear participant,

I would like to firstly thank you for taking part in this online study throughout much of last year. Your commitment to, and interest in, the study was very much appreciated. I am writing to you with a summary of the findings from the study which, aimed to explore what experienced professionals thought were;

- the specific characteristics of adults with Autistic Spectrum Disorder with co-occurring Learning Disabilities ('ASD-LD') which should be taken into consideration when providing sex education
- the adaptations which should be made to facilitate the delivery of sex education for adults with ASD-LD.

Overall, 21 health and social care professionals, experienced in providing sex education to adults with ASD-LD, took part in the first questionnaire, 15 took part in the second questionnaire and 14 took part in the third questionnaire. Also, 12 participants took part in all three questionnaires. This drop-out rate was low, and there were enough panellists to determine a group consensus (i.e. when most professionals agreed on a particular answer; 50% and over).

#### Overall findings:

The analysis revealed very rich and detailed findings, and it is clear that professionals have a wealth of knowledge and experience to share about this topic. Overall, it was found that:

- Professionals agreed that adults with ASD-LD have unique characteristics, and thus require various adaptations to sex education to meet their needs.
- The adaptations rated as important for adults with ASD-LD, differed for those with LD only and ASD only, suggesting those with ASD-LD have additional needs to consider when providing sex education.
- A wide range of sex education topics were recommended.
- Findings emerged about the importance of assessment prior to delivering sex education.

The characteristics and adaptations professionals agreed were most important to consider when adapting sex education related to:

- communication needs
- cognitive and executive functions
- social skill impairments
- sensory needs

Professionals agreed that communication difficulties were important characteristics to adapt sex education for, hence adaptations were associated with using multiple methods of communication. Professionals agreed that individuals with ASD-LD have; cognitive and executive functioning difficulties (e.g. attention, information

processing, short-term memory, a concrete thinking style and difficulties understanding abstract concepts, difficulties generalising learning to different contexts). Hence, adaptations considered important were associated with; making abstract concepts concrete, reducing distractions, repetition and revision of information in multiple formats, breaking information into smaller chunks, tailoring the pace and length of sessions, and involving the individuals' system (e.g. family and carers) to reinforce key messages.

Professionals agreed that social impairments (e.g. difficulties developing relationships, poor understanding of social rules, difficulties with empathy) are important characteristics for which sex education needs adaptation (e.g. concretely teaching appropriate behaviours and social cues in different relationships). Using Social Stories was also considered particularly important because they could be adapted for the social, communication and cognitive needs for adults with ASD-LD.

Professionals agreed that adults with ASD-LD are more likely than others to experience sensory sensitivities, which may negatively impact sexual contact (e.g. finding kissing aversive). Therefore, support with fulfilling their sensory needs in safe and socially acceptable ways is an important adaptation for this group.

Professionals had the most variable beliefs about the value of group-based programs. Overall, they were considered as non-essential adaptations for adults with ASD-LD, as they may become distracted by others and find social interaction difficult. Also, groups can limit educators from flexibly adapting sex education to meet individual needs. Despite this, some professionals believe groups can normalise adults with ASD-LDs difficulties and they can learn from others.

As the majority of adaptations (67/70) were rated as important for adults with ASD-LD, the adaptations were categorised in terms of their level of importance. Adaptations were considered 'Essential' if more than 80% of professionals agreed it was important (see Table 1; the four highest rated adaptations are in bold).

**Table 1: Adaptations categorised as 'essential' for adults with ASD-LD**

<u>Adaptation themes:</u>	<u>'Essential' adaptations</u>
Cognitive and executive functioning	Deliver teaching in distraction free settings.
	Break down information into chunks.
	Build in revision of previous sessions to aid memory.
	Use frequent repetition and rehearsal of content to aid memory.
	Adapt number of sessions to individual needs.
	Adapt length of session to individual needs.
	Focus on one idea at a time.
	Adapt to individuals' attention and memory abilities.
	Use repetition of material in different ways to aid memory.
Communication	Check understanding before moving onto a new idea.
	Make materials accessible to individual.
	Use clear and simple language.
	Use visual aids to support communication.
	Use pictorial aids.
	Use pictures to teach anatomy.
	Adapt communication to individuals own communication methods.



	Use easy read materials.
	Frequently check understanding.
	Use multiple methods of communication.
	Use model penis to practice condom application / to demonstrate sexually transmitted infection transmission.
	Use consistent language.
Making abstract concepts concrete	<b>Avoid abstract and jargon language.</b> <b>Use concrete examples of abstract ideas.</b>
Videos and DVD	Use videos / DVD to reinforce learning.
Social Stories and scenarios	Use scenarios and Social Stories to simplify complex social situations, and enable the individual to problem solve. Use Social Stories and scenarios to explain boundaries and how to keep safe. Use Social Stories to aid memory and recall of taught information. Use Social Stories to help individuals manage their anxiety in social situations. Use social stories.
Role-play	Use role-play
Routine / planning of sessions	Develop clear aims for each individual. Prepare individual for session endings and changes to plans.
Boundaries	Be clear on educator's role and boundaries (e.g. remind individual that educator cannot be in sexual relationship with individual). Provide session rules.
Published resources	<b>Flexibly adapt existing published resources to the individual.</b>
Working with the person's system	<b>Educate and support professionals/carers/ families to develop more positive attitudes towards sex and relationships for this group.</b> Provide systemic consultation with professionals/ carers/ families. Involve professionals/carers/ families in sex education intervention to enable generalisation of learning outside of sessions.

Professionals also recommended a wide variety of topics, relating to; the body, functions of sex, relationships, interpersonal skills, appropriate and inappropriate behaviours and their consequences, understanding social cues and emotions, enjoyment of sex, safe use of social media and communication technology, safe sex, sexual health, sexuality, and sensory issues relating to sexual contact.

Assessments considered by professionals as most important were; assessing individuals'; current knowledge, suitability to a group or individual sex education intervention, communication abilities, background history, needs and preferences, risk, cognitive abilities, and the possible emotional impact or timing of the provision of sex education. The most common assessment method was to meet and interview the individual.

#### Further dissemination:

As you are aware and have consented to, this research will aim to be published in a journal. However, we have been so impressed by the rich information which the participants kindly contributed, which can only be represented partially here, that we believe the findings have potential to be developed into a sex education manual for professionals on ways to adapt sex education for adults with ASD-LD. Therefore, your anonymous responses could form part of the manual. If you do not consent to this, or would like to discuss this further, please contact me by the end of June 2017. Thank you for participating in this study. I hope you have found it a valuable

experience, and that the findings will help professionals to adapt sex education for adults with ASD-LD, and encourage further research in the area.

If you have any questions, please contact me at [k.c.taylor214@canterbury.ac.uk](mailto:k.c.taylor214@canterbury.ac.uk) or on 07738377660.

Kind regards,

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## Appendix K: Examples of theme development

### Example 1 - Concrete thinking

Category	Theme	Code	Example of an extracted quote
Characteristics	Concrete thinking	Concrete thinking	“There can be a tendency for people with ASD to think in very concrete ways”
		Difficulties with abstract and ambiguous concepts	“People with ASD and LD struggle with abstract concepts”
		Literal interpretations of language	“Be mindful of the possibility of the individual’s literal interpretation of information”
		Difficulties generalising learning to different contexts	“People in this population may also have difficulty generalising knowledge learnt in one setting to another”

### Example 2 - Make abstract concepts concrete

Category	Theme	Code	Example of an extracted quote
Adaptations	Make abstract concepts concrete	Avoid abstract and jargon language	“jargon or euphemisms should be avoided”
		Use literal and concrete language	“Language needs to be direct, concrete and literal. it is important to always state the obvious”
		Use concrete examples of abstract ideas	“Concrete information reduces difficulties with abstract ideas”
		Use tangible teaching aids to make abstract information concrete	“It is helpful to use visual, physical or audio teaching aids during sessions as this helps to make an abstract topic more concrete and tangible for the individual.”
		Explicitly teach how to recognise social cues in different relationships	“Many of the individuals that I have worked with have told me either during or on conclusion of work that they found having information on specific aspects of social and sexual relationships, emotion awareness and recognition guidance, non-

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	verbal cues for people's emotions and behaviour, guidance on what is socially appropriate and inappropriate and sexual relationships and activity knowledge very helpful"
Explicitly teach which behaviours appropriate/inappropriate in different relationships	"As mentioned previously, sex education may need to be more prescriptive and explicit for this client group, as people will rely on clear rules for behaviour. Subtle allusions to correct behaviour will not be appropriate as they may be misunderstood or completely missed"

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### Appendix L: List of sex education topics recommended by panellists

Topic theme	Topic code
Physical body	Aging and development Body parts Functions of body Menstruation Wet dreams Personal care and appearance
Enjoyment of sex	Normalising sex Sexual positions How to participate and enjoy sex What are sexual feelings Recognising when sex is not enjoyable or painful
Different types of sexual behaviours	Sex terminology What is sex Intercourse and the mechanics of sex What is masturbation How to masturbate Where it is appropriate to masturbate
Pregnancy	Having a family Reproduction and conception Birth How to get help when pregnant
Safe use of social media and communication technology	Phones and texting Internet Facebook
Different types of relationships	Friends Dating partners Boyfriend/ girlfriend Professional
Boundaries in different relationships	Who you are allowed to have sex with Appropriate and inappropriate behaviours in different relationships Power dynamics in relationships Inter-personal space Good and bad touch
Maintaining safety in relationships	Partner consent Own consent and making informed choices Good and bad touch Assertiveness / saying 'no' Recognising what sexual abuse is Where to get help for sexual abuse/exploitation How to identify and avoid exploitation

Interpersonal skills in different relationships	<ul style="list-style-type: none"> <li>Not being controlling</li> <li>Appropriate communication with others</li> <li>Dealing with rejection</li> <li>Accepting no as an answer</li> <li>Ending relationships</li> <li>How to make friends</li> <li>Conversation skills</li> <li>How to negotiate more intimate contact with others</li> <li>Understanding other peoples' perspectives</li> <li>Problem solving in relationships</li> </ul>
Reading social cues	<ul style="list-style-type: none"> <li>Interpreting body language and non-verbal communication</li> <li>Recognising others emotions</li> </ul>
Appropriate and inappropriate behaviours in different situations	<ul style="list-style-type: none"> <li>Appropriate/inappropriate behaviours in different situations</li> <li>Public and private spaces</li> </ul>
Safe sex and sexual health	<ul style="list-style-type: none"> <li>Contraception</li> <li>Sexually transmitted diseases</li> <li>Maintaining own physical health</li> </ul>
Sexuality	<ul style="list-style-type: none"> <li>Gender identity</li> <li>Sexual orientation</li> <li>Sexual preferences</li> <li>Unusual sexual arousal and preferences</li> </ul>
Consequences of own behaviours	<ul style="list-style-type: none"> <li>Negative consequences of behaviours</li> <li>Impact of behaviours on others</li> <li>Impact of behaviours on self</li> <li>Sex and the law (legal implications)</li> </ul>
Sensory issues relating to sex	<ul style="list-style-type: none"> <li>Unusual arousals</li> <li>Explore any sensory issues relating to masturbation</li> </ul>
Managing own emotions	<ul style="list-style-type: none"> <li>Coping skills and managing difficult emotions (e.g. anger, anxiety)</li> <li>Recognising own emotions</li> <li>Managing own impulsive behaviours</li> </ul>

**Appendix M: List of sex education session rules recommended by panellists**Session rules

- No offensive / disrespectful language
- Listen to each other
- Take turns to talk
- Respect each other's differences
- You can disagree with others
- Maintain confidentiality
- Maintain confidentiality unless there are safeguarding concerns
- You can have breaks
- The individual is in control
- Importance of punctuality and attendance
- Give notice if they need to cancel a session
- No sexual behaviour in sessions
- No touching others in sessions
- What to do if distressed or uncomfortable in the session
- They can end the session if they feel uncomfortable
- What to do if aroused in session
- Maintain educator boundaries (i.e. no sexual behaviour or relationship with educator)
- Discourage relationships between service users in group sessions
- The individual can ask any question
- This is a 'safe space' (i.e. to enable the individual to feel safe in the session)
- To check with the individual before showing pictures or resources
- No mobile phones in session

**Appendix N: List of ways to involve the individuals' system in sex education recommended by panellists**

Ways to involve individuals' system (e.g. family, carers, professionals)

- Invite family / carers to individual sessions
- Set homework with family / carer support
- Family / carers can reinforce learning outside sessions
- Develop positive relationships with system
- Share session plans with family / carers
- Provide families feedback / progress from sessions
- Share session materials /resources with family / carers
- Share information / strategies from session with family/carers to enable reinforcement outside sessions
- Carers and support workers to provide support in group interventions
- One-to-one support from carers in groups are helpful
- Gain consent for individual for family/carer involvement
- Ensure confidentiality is maintained
- Provide training on sex and relationships education for family /carers
- Consult with family / carers separate from individual
- Run support groups for family / carers



## Appendix O: End of study summary to university ethics panel

Dear ethics panel chair,

Study: Sex education for adults with Autistic Spectrum Disorder and Learning Disabilities

### Overview of study:

#### Aims:

This study aimed to identify whether consensus between experienced professionals could be gained on the best methods to adapt sex education for adults with autistic spectrum disorder with covarying learning disabilities (ASD-LD). This study adopted a three-round, electronic Delphi methodology to address the research questions:

- 1) What are the specific characteristics of adults with ASD-LD that should be taken into consideration when providing sex education?
- 2) What adaptations, if any, do professionals consider should be made to facilitate the delivery of sex education for adults with ASD-LD?

#### Method:

In total, participants consisted of 21 health and social care professionals, who currently or had previously worked in or with specialist ASD or LD services and had experience in providing sex education to adults with ASD-LD. Participants were sent three-rounds of questionnaires. The main concepts from the qualitative responses from the first questionnaire were fed back to participants in the second questionnaire as statements. Panellists rated the level of their agreement with these statements, and answered additional open-ended questions. The responses from the second questionnaire mostly reached group consensus, therefore, the third questionnaire involved participants clarifying areas of divergence and consensus, and speculating on a selection of these results. In all questionnaires, panellists were given the opportunity to add any further comments.

#### Findings:

Overall, the rich data revealed that experts in the field have a vast amount to share on the topic, and agree that adults with ASD-LD have unique characteristics, and thus require various adaptations to sex education to meet their needs. Also, the findings reflect the literature which suggests individuals with ASD-LD are a distinct group with unique needs, compared to those with LD or ASD (Matson & Shoemaker, 2009).

Participants agreed that adults with ASD-LD have unique characteristics, and thus require various adaptations to sex education to meet their needs. The adaptations rated as important for adults with ASD-LD, differed for those with LD only and ASD only. This suggests that those with ASD-LD have additional needs to consider when providing sex education in comparison to those with LD or ASD only. Additionally, wide ranging sex education topics were recommended, and findings emerged about the importance of assessment prior to delivering sex education (e.g. assessing individuals' knowledge, communication abilities, etc.).

The characteristics and adaptations participants agreed were most important to consider when adapting sex education related to communication needs, cognitive and executive functions, social skill impairments, and sensory needs. Participants agreed

that communication difficulties were important characteristics to adapt sex education for, hence adaptations were associated with using multiple methods of communication. Participants agreed that individuals with ASD-LD have cognitive and executive functioning difficulties (e.g. attention, information processing, short-term memory, a concrete thinking style and difficulties understanding abstract concepts, difficulties generalising learning to different contexts). Hence, adaptations considered important were; making abstract concepts concrete, reducing distractions, repetition and revision of information in multiple formats, breaking information into smaller chunks, tailoring the pace and length of sessions, involving the individuals' system (e.g. family) to reinforce key messages. Participants agreed that social impairments (e.g. difficulties developing relationships, poor understanding of social rules) are important characteristics to adapt sex education for (e.g. concretely teaching appropriate behaviours and social cues in different relationships, using social stories). Participants agreed that some adults with ASD-LD experience sensory sensitivities, which may negatively impact sexual contact (e.g. finding kissing aversive), adaptations should include supporting them to fulfil their sensory needs in safe and socially acceptable ways. Participants had the most variable beliefs about the value of group-based program, which were considered non-essential adaptations for adults with ASD-LD.

#### Implications:

This study revealed the importance of considering individuals with ASD-LD as a distinct group with unique needs (Matson & Shoemaker, 2009), for which sex education interventions should be adapted for to meet these needs. There is scope for disseminating the findings as professional guidelines for sex education interventions for adults with ASD-LD.

Future research could focus on investigating whether these adaptations to sex education lead to increased knowledge and applied skills in this population, to seek the views of individuals with ASD-LD on these adaptations, and investigate the impact of sensory sensitivities on this population's ability to engage with sexual behaviours.

Kind regards,

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#### References:

Matson, J. L., & Shoemaker, M. (2009). Intellectual disability and its relationship to autism spectrum disorders. *Research in Developmental Disabilities, 30*(6), 1107–1114. doi: 10.1016/j.ridd.2009.06.003

## Appendix P: Author guidelines of journal chosen for submission of empirical paper



### British Journal of Learning Disabilities

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