‘Let’s talk about sex’: A case study of relationship and sex education (RSE) for young people with a diagnosis of an autism spectrum disorder (ASD).

By

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ABSTRACT

The existing literature points to a ‘paucity of research relating to sexuality, RSE and ASD’ (Hartman, 2014), compared to sexuality of people with other developmental/learning needs.

Research indicates that parents are generally best placed for delivering RSE to their children, though are not always equipped to do so. However, the onset of the new government legislation in 2019/20, will see the delivery of RSE becoming part of the remit of school staff.

The present study explored the delivery of RSE within one local authority in the East of England to pupils with ASD attending mainstream schools. Views of parents and young people diagnosed with ASD, as well as staff were explored. Additionally, educational psychologists as well as the Autism Outreach Service were also included to explore their role, if any, in the future delivery of the new RSE curriculum.

Methodology: A case study design was employed. A mixed methods approach was adopted to gather data through the use of focus group interviews, individual interviews and questionnaires. Qualitative data was analysed using thematic analysis as described by Braun and Clarke (2006), across the groups. Descriptive statistics were used for quantitative data.
Results: Two overarching themes were found - Positive Perceptions and Collective responsibility. Within this local authority there were quite positive views of RSE and a feeling that there was a definite need to deliver this curriculum with a responsibility on everyone’s part to do so.

Conclusion: The thoughts and views of the different interest groups within this local authority were quite progressive and seem to have so far, had a positive impact on current delivery of RSE to pupils with an ASD diagnosis. The findings and their implications for the role of educational psychologists are considered within the current landscape of the changing curriculum.

Key terms: autism, sex education, sex, sexuality, relationships, RSE
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CHAPTER 1: INTRODUCTION

1.1 Rationale for Study

As a Teaching Assistant (TA) working within the same local authority where the current research is to be carried out, the researcher was tasked with delivering a curriculum of Sex and Relationship education to a group of 5 Year 9 pupils with a mix of Special Educational Needs (SEN). The other TA who was to assist flatly refused to do so after seeing the proposed curriculum and resources citing that it was just too explicit. Luckily the SENCO had the foresight to see the need for this curriculum to be delivered and so, together with the researcher, gave these pupils some much needed guidance and direction. The pupils gained much from the sessions and the experience left the researcher wondering just how many other young people may be missing out because of the attitudes/views of staff.

During the first year of the doctoral training, the researcher delivered a seminar on the topic ‘Sex and Relationship Education for children with SEN’ and highlighted the previous experience and benefits of delivering this curriculum. The feedback was quite good and it was recommended by the course tutor as a potential area for research particularly given that there was not much on the topic within the field of educational psychology. This, together with the experience as a TA, led the researcher to consider the topic of Sex and Relationships for the current research. The topic was narrowed to just young people with Autistic Spectrum Disorder as there is a paucity of research for this group in particular.
Additionally, the researcher discovered that changes were due to be made to this curriculum around 2019/20 making it a compulsory subject area across schools in England so it was felt that the topic was current and that the research would be well-timed and well placed to inform delivery of this curriculum to young people with ASD attending mainstream provision.

1.2 Definition of terms used

1.2.1 Defining ASD

Autism Spectrum Disorders (ASD)

For the purposes of this paper, ASD would be the term used to refer to the different diagnostic labels and would include autism, autistic spectrum condition (ASC), Asperger syndrome and high functioning autism (HFA).

The National Autistic Society (NAS) defines autism as a “lifelong, developmental disability that affects how a person communicates with and relates to other people, and how they experience the world around them”. ASD is very common, affecting about 700,000 people in the UK (National Autistic Society, [NAS], 2017). The World Health Organization (WHO, 2017) reports that ASDs have been increasing globally and that 1 in 160 children now has an ASD. Generally, there are more males diagnosed with the condition than there are females, five times as many according to the latest NAS figures, but this could be due to the under-
diagnosis of females and not necessarily because it exists more in males (Gould and Ashton-Smith, 2011).

ASD is often characterised by impairments within three categories: social communication, social interaction and restrictive and repetitive patterns of behaviours, activities or interests (as specified by the International Classification of Diseases- ICD-10 [2016 Version]), commonly used for diagnosis in the UK). It is the impairment in social interaction and communication that often leads to difficulties in maintaining relationships making those with ASD particularly vulnerable to difficulties in the area of sex and relationships (Byers et al., 2013).

As ASD is a ‘spectrum’ condition, there is usually great variation amongst those diagnosed with the condition. While they may share certain qualities, they can usually be affected in different ways with a range of abilities /disabilities, requiring different levels of support.

1.2.3 Relationship and Sexuality Education

Relationship and Sexuality Education (RSE) is used in this research to replace ‘sex education’ which could be misconstrued as being simply about sexual intercourse. This misperception of the term can often lead to this programme of study being side-lined at school and in the home. The use of RSE however, implies a much broader curriculum with an emphasis on relationships, identity, love, intimacy and safety (Hartman, 2014). Hartman sees the primary goal of RSE as supporting the development of a healthy sexuality which includes an ability to develop and sustain meaningful relationships, an understanding of one’s changing
body, and an ability to make informed decisions and express sexual feelings in a socially acceptable manner.

The reality at the moment is that many typically developing young people do not receive adequate RSE (Hartman, 2014) and the situation is even worse for those with special needs. Alford (2008) contests that young people who have little RSE are more likely to engage in early sexual behaviour and make poor choices with regards to contraception whereas those who have been taught about their sexuality in a manner appropriate to their age and development are well poised to develop healthy sexual relationships.

1.2.4 What is meant by ‘SEXUALITY’

Bruess and Greenberg (1994) describe sexuality as behaviours which comprise of physical, emotional and social interactions all at play simultaneously. Koller (2000) adds that sexuality can be critical to the development of a positive self-esteem, encompassing self-image, values, attitudes and beliefs. Sexuality is seen as being different from a typical friendship as friendships do not usually involve physical intimacy and the type of emotional commitment that may be required for a sexual relationship. Sexuality is fluid, changing continuously in response to our interactions and experiences (Koller 2000). Understanding one’s sexuality involves a certain level of sexual awareness/consciousness and ‘perception of sexual situations, feelings, motives and desires surrounding sex’ (Hannah and Stagg, 2016).

Snell et al. writing in 1991, proposed that an individual’s sexual awareness and assertiveness was a function of their cognitive attentional processes. They saw four cognitive processes
involved in sexual awareness: (a) *sexual-consciousness* – a person attends to their internal sexual cues, for example, bodily sensations, and reflect on their own sexuality; (b) *sexual-monitoring* – a person’s ability to be aware of how their sexuality is viewed by others; (c) *sexual-assertiveness* – a person’s tendency to display assertiveness in their sexual decision making; (d) *sex-appeal consciousness* – an awareness of how one’s sexiness is perceived by others. It follows therefore that for those with ASD who struggle with self-awareness (Verhoevan et al. 2012) and with attributing mental states to others (Baron-Cohen et al. 1985), developing sexual awareness as described by Snell et al.’s cognitive processes would be a momentous task.

1.3 RSE and Disability

Traditionally, individuals displaying a disability have been thought of as being sexually immature, lacking interest in sex and sexuality, and being sexually ‘insignificant’ (Konstantareas and Lunsky, 1997). As a result of these social myths, coupled with personal discomfort and insufficient knowledge, these individuals have been denied access to RSE in the past.

Studies now show that young people with disabilities are at an increased risk of sexual abuse (Blum et al. 2001; Mandell et al.2005), and unwanted pregnancies (Levy et al., 1992). Statistics report a figure for those with disabilities that is higher than the 20% to 25%, which is reported for children without disabilities (Koller 2000). Furthermore, young people with disabilities are likely to be just as sexually active as their non-disabled peers. Despite this however, they are not targeted for ‘prevention interventions’ in the same way as their non-
The existing literature points to a ‘paucity of research relating to sexuality, RSE and ASD’ (Hartman, 2014), compared to sexuality of people with other developmental/learning needs (Sullivan and Caterino, 2008; Koller, 2000; Hartman, 2014). This was due in part to the prevailing misconception that persons with ASD had no sexual interest or were unaffected by sexual desires (Sullivan and Caterino, 2008).

It is now acknowledged that young people with ASD undergo and experience puberty and its related physiological fluctuations, including sexual urges, emotional and hormonal changes (Tullis and Zangrillo, 2013), in much the same way as their typically developing peers. Furthermore, they do want to engage in intimate relationships and are neither hypersexual nor asexual (Gougeon, 2010).
CHAPTER 2: LITERATURE REVIEW

2.1 A systematic search

An initial search was conducted using the terms ‘autism, sex, sexuality, education’ in the University of Sheffield’s Starplus Library search engine in the ‘University Collections’ tab which yielded 0 results. The ‘Articles and more’ tab was then used and this yielded 4,237 hits. The researcher limited this to peer reviewed journals which yielded 1,246 hits. The search was narrowed further to articles between the years 2000 and 2017 and this yielded 979 results. The researcher then searched within the topic ‘psychology’ and this brought the results down to 147. However, articles were being listed with only one of the search terms in the title and were not always relevant to the topic.

Added to this the researcher used other online databases such as PsychSource and explored the Association of Educational Psychologists (AEP) online journals, Educational Psychology in Practice (EPIP), as well as the British Psychological Society’s (BPS’s) Journal of the Division of Educational and Child Psychology (DECP). Using similar search terms and limits as above, and using the topic ‘Psychology and Behavioural Sciences collection’, the researcher was able to narrow the search to 396 hits on PsychSource. There was not very much specific to educational psychology. Only one hit was found from the search of EPIP journals, and one hit from the DECP journal. For further exploration, and in an attempt to exhaust the search, terms were linked together such as ‘autism and sex education’. Secondary references were
also used and some of these were before the year 2000 which was initially the lower year boundary.

The review of literature found that there was a paucity of research specifically related to RSE for adolescents with ASD. Furthermore, within the field of educational psychology, research was almost non-existent. The one hit from the EPIP journal was a book review of a text written by Senior Educational Psychologist, Davida Hartman (2014), which is referred to later on in this literature review. The DECP journal search brought up an article linked to the term ‘sexuality’ but this was more to do with the ‘constructions’ of sexuality by educational psychologists rather than RSE.

Based on the search, the researcher decided to use articles/literature referenced in the Hartman (2014) text as well as any other literature that was brought up in the search. There was a most recent study conducted after Hartman’s review and this was of particular interest to the researcher as it gained the views of young people with ASD. It was decided to choose a few pertinent and more recent articles and analyse the studies in terms of involvement of young people with ASD, size of study, results obtained and limitations. Pertinent points arising from the studies were used as sub-headings for discussion throughout the rest of this review.

### 2.2 Problematic sexual behaviours

One of the core elements of ASD is the poor understanding of social interactions and an inability to read non-verbal social cues. Adolescents with ASD often display deficits in understanding receptive and expressive language (Henault, 2006) and so are unable to fully
participate in all aspects of adolescent life, particularly, forming and maintaining relationships (American Psychiatric Association [APA] 2013), limiting their experience of social interactions. As these young people grow into adults, their deficits become more pronounced as does the complexity of their sexuality (Stokes and Kaur, 2005).

As a result, young people with ASD are prone to all sorts of difficulties in relationships, particularly those of a sexual nature (Byers et al. 2013). This lack of social judgement also increases vulnerability and leads to a high risk of sexual abuse and victimisation (Brown-Lavoie et al. 2014).

Robyn Steward (2014), a young woman with Asperger’s Syndrome and author of ‘The Independent Woman’s Handbook for Super Safe Living on the Autism Spectrum’, writes about her own sexual abuse resulting from her ASD difficulties, supporting Brown-Lavoie et al’s (2014) claim. Steward (2014) spoke of her experiences at a recent conference (July 2017) of the AEP’s Educational Psychologists Autism Special Interest Group (EPASIG) on the topic “Autism, Sexuality and Relationships” and stressed the importance of educating girls on the spectrum in particular (but boys as well) on their sexuality and of phenomena such as ‘body language’, so they are not naive to the social cues, signs and innuendos that can present problems from a safety perspective.
2.3 A role for parents and caregivers

The Sexuality Information and Education Council of the United States (2012) recommends that parents are the primary sex educators for their children with communication about sex beginning in early childhood and progressing through to adulthood. Parents are seen as the experts on their children and will be in a position to developmentally tailor their discussions, choosing what topic to discuss, at what age and to what extent (Holmes et al. 2016). This is a difficult task for most parents but particularly so for parents of children and young people with ASD where there is a tendency for physical development to be out of sync with and outpace emotional development (Ballan 2012).

A survey of 100 parents of ASD youth conducted in 1993 by Ruble and Dalrymple, found that parents had a number of concerns regarding sexuality, the most common ones being that their child’s nonsexual behaviour would be misconstrued as sexual, that sexual behaviours would be misunderstood and that their child would be subject to sexual abuse and exploitation. Recent studies are consistent with these previous findings and Holmes et al. (2016) explains that understanding these concerns are important as they can influence the extent to which a parent engages in ‘parent-child sexuality communication’ (PCSC). For example, Ballan’s 2012 study found that concerns can impede rather than motivate parents to engage with their children in matters of sexuality as some fear their child may become fixated with the topic if exposed to it (and so inclined) or may seek masturbation, after learning about it, as a self-stimulating behaviour.
Fortunately, though, most parents report engaging in some way with sexuality with their ASD children. Holmes and Himle, (2014) surveyed 198 parents of adolescents with ASD and found that most parents covered the basics (about 90%) but less than half delved into topics such as how to decide whether to have sex (48.8%) or how to ask someone out on a date (45.4%).

Indeed, quite a few studies point to a role for parents and carers in facilitating the RSE of their ASD children and young people. Among these is a study by Koller (2000) who makes regular reference to education for caregivers of individuals with autism who often express concern about being embarrassed by the behaviour of the individuals in their care. This is reported to be a particular concern for boys with ASD who may often expose themselves and self-stimulate/masturbate in public. The focus of Koller’s study was on the parent/carer’s perspective and how they could support their young person with various aspects of RSE learning, but the study lacked views of the ASD young people themselves.

Another parent-focussed study was a two-part exploratory study conducted by Nichols and Blakeley-Smith in 2010. However, the aim was not only to explore the views of parents regarding the sexuality of their ASD children, but also to develop a parent sexuality-education curriculum to increase parents’ comfort level with the topic and then evaluate the curriculum’s implementation after 8 weeks.

Participants comprised of 21 parents of children aged 8-18 with a clinical diagnosis of ASD (including autism, Asperger’s disorder, or pervasive developmental disorder-not otherwise specified {PDD_NOS}). The children’s cognitive abilities were determined by full-scale IQ
scores which ranged from ‘severe delay’ to ‘above average’ Parents were assigned to one of three focus groups based on their child’s chronological age (8-12 years, 13-15 years, 16-18 years) and verbal cognitive skills. Focus groups were for a single session lasting 1.5 to 2 hours and they were audio-taped. There were four stages to the focus groups. Stage one was the introduction and included clarification of the term ‘sexuality’ which researchers acknowledged was often misconstrued from a narrow perspective to mean ‘intercourse’ and just physiology, biology and behaviour. Researchers hoped to broaden parents’ thinking by providing handouts of the various dimensions of human sexuality. Stage two was dubbed ‘transition’ and here parents shared information about their children and why they wanted to be involved in the focus group. Initial themes were gathered at this stage. Stage three was the ‘In-depth investigation’ where participants were probed on specific questions and asked to ‘brainstorm’ on sheets of paper prior to discussion. Stage four was the ‘wrap-up’ where additional comments could be added or alterations made and the session was summarised.

Each focus group had an observer/recorder who made notes of salient points with examples. Note-based analysis was employed to derive themes and patterns and audio was used for clarification and for direct quotes. Six main themes/patterns emerged which were consistent with previous findings of concerns for the misinterpretation of their child’s behaviour. However, there were additional concerns for the potential legal consequences for their child resulting from their ‘inappropriate’ and ‘harmful’ behaviour. Parents saw a need to position themselves as advocates and protectors for their children and to equip themselves with the necessary knowledge, skills and resources to provide RSE.
Arising from these concerns, an 8-week parent education group curriculum was developed and involved two parent groups of five parents each. A ‘Parent comfort ratings’ questionnaire and some qualitative data was also obtained. Some parents had described themselves as being anxious when it came to discussing the topic of sexuality and had set this as the primary goal of their involvement. Results showed significant increases in average comfort ratings for discussing sexuality in a group (p<.02) and with school staff (p<.03). Parents most enjoyed hearing others’ experiences and the opportunity to problem-solve together. They appreciated working with a supportive professional who shared information and materials that they could take away and share with their child and their school.

This study was limited by its small sample size which has been a factor in many studies within this field. Additionally, participants were volunteers and there was no control group for comparison. Notably, the study concentrated on parents’ comfort level and did not assess their abilities in actually delivering RSE to their children, by measuring their progress in some way, perhaps through goal attainment scaling for example.

A further experimental study that placed importance on the role of parents in delivering RSE to their ASD children was that of Ballan, 2012. Ballan cited communication between parents and their children as a protective factor in reducing risky sexual behaviour among youth generally, though at the time of her study, this protective function between parents and children with ASD was not explored. Ballan set about to understand this parent-child communication with regards to sexuality for children with ASD. In addition, Ballan was aiming to develop a parent-based intervention programme. The methodology chosen for
Ballan’s study was in-depth interviews using semi-structured questioning. Nineteen participant parents representing 20 children with a clinical diagnosis of ASD (16 fully schooled in mainstream settings with support, and four in special education/resource units attached to mainstream schools,) aged 6 to 13, took part in the study. Nineteen of the 20 children were able to communicate using spoken language. Content analysis was used by 2 independent coders to aid reliability and there was an agreement rate of 94%. Emergent themes included: misperceptions of children’s non-sexual and sexual behaviour, challenges in addressing sexuality with their own children as well as professionals, sexuality information communicated to children, and perceptions of children’s future influencing communication topics.

Ballan described her study as being innovative, addressing a gap in the literature and helping to shed light on the ‘sexual risk reduction needs’ of ASD youth and the possible ‘protective’ role of parental involvement. It was noted that parents struggled to envision a romantic future for their children which Ballan saw as being striking. The study suggested that programmes to assist parents’ delivery of sexuality should try to enhance their self-efficacy with communication, as parents often felt ill informed and under prepared.

The qualitative methodology of this study however, meant that the small sample size of 19 participants had the consequent problems of trying to generalise the results to all parents of children with ASD. Additionally, the study was about the parental views and not those of the ASD youths themselves. Parents were mostly mothers (16 of the 19) of boys with ASD, only one child was female. Mothers can often find it difficult to discuss matters of a sexual nature with their sons under normal circumstances so the data gathered could be
misrepresentative in that if more fathers were involved in the study, communication may not have emerged as such a major theme.

Holmes et al. (2016) also looked into the role of parents and their sexuality-related concerns for their children with ASD and here again parents expressed concerns about their self-efficacy and preparedness for addressing their child’s sexual development. Holmes et al. saw a role for the cognitive and communication abilities of the child with ASD as impacting on the concerns of the parents, and ultimately the nature of the RSE delivered. Holmes et al’s study was centred on adolescents (12-18 years) with parent-reported average or above intelligence and no comorbid intellectual disability, the first to thoroughly examine parental concerns for ASD adolescents of average or above intellectual functioning and the significance of these concerns to the parent’s ability to engage in parent-child sexuality communication (PCSC). 131 parents (of mostly male adolescents with ASD) participated in an online survey made up of a Social Responsiveness Scale – 2\textsuperscript{nd} edition (parent report) (SRS-2), an online sexuality survey, a Parental sexuality concern inventory and a parental sexuality education inventory. Analysis was by way of a principal component analysis and yielded four sexuality-related concern factors: Concerns about negative outcomes; Concerns about sexual deviance; Concerns about relationships; Practical concerns and expectations.

This was a quantitative study that aimed to shed light on previous qualitative research (Ballan, 2012; Nichols and Blakeley-Smith, 2010; Ruble and Dalrymple, 1993) by quantifying the frequency and intensity of parental concerns and looking at how they might impact on PCSC. Because it was quantitative, the study also had the largest sample size (N=131) of any study found for this literature review. The study revealed that parents had great concern
(90.7%) about their children’s future romantic relationships and partnered sexual experiences consistent with the previous research, but where the child’s communication and cognition needs were more severe, parental concern was greater. 89.9% of parents surveyed were doubtful of their child’s ability to have/sustain any kind of emotionally fulfilling relationship which we know can lead to social isolation, resulting in loneliness and depression (Mazurek 2014). The impact this can have on mental health and well-being has implications for all who work with CYP with ASD with regards to providing the necessary teaching for relationships and sexuality.

A primary aim of this study was to examine the impact of parental concerns on PCSC. Previous studies gave rise to the view that concerns by parents could impede PCSC (Ballan, 2012). An alternative view could be that parental concerns would be a motivator as they seek to protect their children from the potential risks (Holmes et al., 2016). The study found no strong association between parental concerns and PCSC meaning that ‘parental concerns’ was not as important a factor in PCSC when compared to other variables such as age of the child, or severity of ASD symptom, for example.

Limitations of this study laid mostly with the participants. Though a larger sample size, the participant number (N=131) was still small. Recruited online, the sample would have been restricted to those with computer and internet access, and quite possibly, those of affluence. Holmes et al. themselves mention that participants were all ‘white, married and well-educated’, which is hardly indicative of the general population. Additionally, participants were all volunteers and Strassberg and Lowe (1995) report that volunteers for sexuality studies are often more comfortable with sexuality anyway compared to the
general public and so these parents may have had a different approach to their child’s sexuality. Finally, like in so many other studies, the gender of the parents participating was predominantly female (92.2%) and the children, predominantly male (87%), and this has been seen to be an important variable in PCSC (Diloro, Pluhar and Belcher, 2003), leaving the female ASD population underrepresented.

2.4 Self-perceptions of sex and sexuality

A most recent study conducted in the UK by Hannah and Stagg in 2016, sought to address some of the shortcomings of research thus far by exploring the self-perceptions of sex and sexuality of young people with ASD and their experiences of RSE when they attended school. This was quite relevant as previous studies tended to focus on sexual experience or sexual behaviour (Hartman, 2014; Hannah and Stagg, 2016), which included information on frequency of sexual behaviour and lack of sex education. Additionally, most of the data in previous studies was gained from professionals working with young people with ASD or from parents and so were the perceptions of others and not of the young people themselves.

This mixed-methods comparative study looked at forty young people in the 18 – 25 age group, a group recently included in the Special Educational Needs and Disabilities (SEND) Code of Practice (2015) and an age group for whom RSE is most relevant. The study involved twenty participants with a diagnosis of ASD (no further information is given) and twenty
typically developing individuals. Participants were both male and female though there were more male participants in the ASD group (12 males to 8 females) than in the typically developing group (7 males to 13 females). The use of majority male participants was prevalent in previous studies, perhaps because of the male-female ratio within ASD. This gender bias was compensated for by the use of a Pearson’s Chi square test which made gender independent from the group. From the twenty participants in each group, four males and four females took part in the qualitative element of the study, so here there was a gender balance. No participant had an intellectual impairment.

Participants completed self-report measures. These included a Sexual Knowledge, experience, feelings and needs scale (SexKen, McCabe et al., 1999), as well as The Sexual Awareness questionnaire (SAQ, Snell et al., 1991).

The qualitative aspect of the study involved individual semi structured interviews of 10 to 15 minutes in length. One strength of this study was in stating its ontological and epistemological stance of critical realism where it positioned itself for thematic analysis, which was the method used to make sense of the interviews.

Results showed no statistical difference between the ASD group and the typically developing group in terms of sex education feelings or sex education needs. However, there were significant differences in sexual consciousness, sexual monitoring, sexual assertiveness and sex-appeal consciousness. These findings reflect earlier suggestions that YP with ASD do have similar needs with regards to RSE but that these were not being met, hence the feelings of sexual inadequacy.
The thematic element confirmed the feelings of inadequacy and even vulnerability, expressed by the ASD group, which was notably absent from the typically developing group, where participants felt much more knowledgeable and comfortable with their sexuality. Overriding themes included: dissatisfaction with sex education in school, sexuality (their own sexual orientation), social anxiety, and vulnerability.

While there were attempts in this research to address previous shortcomings, some limitations were identified by the authors themselves. Most notable was the small sample size which always seems to be the case in research in this area, as it almost always tends to be case studies or qualitative, making it difficult for generalisability. Additionally, the qualitative research was conducted with ‘volunteers’ who had already completed the questionnaires so it was hardly a ‘random sample’. Also of note was the absence of any information regarding intellectual ability of participants other than to say they had no intellectual impairment. This was somewhat vague and could have been clarified further as this would have an impact on the results. There are also questions regarding the derived themes as these would have been subject to the researcher’s interpretation. Lastly, the interviews were particularly short lasting no more than 15 minutes and one wonders whether this was sufficient time to fully elicit the views of these young people and get through the 10 semi-structured questions.

Despite this, the study was able to shed some light on the views of young people with ASD and confirmed the need for a tailored RSE programme which addresses sexual awareness, understanding of others and sexual orientation.
2.5 Mental health and well-being

Koller, writing in 2000 in America, saw RSE as an important aspect of mental health and well-being for all individuals but especially so for young people with ASD who could have particular struggles within this area. Koller (2000) sees this need for RSE for ASD youths to become even greater because of inclusivity of these pupils within mainstream settings. Koller (2000) talks of RSE being delivered informally through interactions, observations and social media and explores how this may lead to ‘unhealthy opinions’ of sexuality among ASD youths. Koller (2000) contends that a lack of guidance and relationship support could impact on mental health leading to low self-esteem, depression, isolation and loneliness for these individuals, a position supported by Hatton and Tector (2010). Loneliness is a well-known chronic stressor leading to psychiatric and physical health problems (Mazurek, 2014). A recent study by Crane et al. (2018) also emphasises the importance of having strong, trusting relationships to fostering positive mental health outcomes for young autistic adults.

On the other hand, romantic relationships and sexual contact lead to positive mental health outcomes as well as impacting on physical health. This in turn makes for an improved quality of life with decreased morbidity and mortality (Mazurek, 2014). With such benefits to be had from romantic relationships, it is imperative that research addresses this topic with regards to young people with ASD particularly in light of the UK government’s focus on well-being and mental health, with publications such as No Health without Mental Health (2012) and Future in Mind (Department of Health, 2015), as it recognises the importance of good mental health to improving quality of life for all persons.
2.6 Summary of Research Findings

These studies provide a strong case for the delivery of RSE, either by parents of pupils with ASD, or through the school curriculum. Studies have shown that adolescents with ASD are indeed sexual beings just like the rest of us and they should be taught how to handle their sexuality appropriately (Koller 2000; Sullivan and Caterino, 2008).

The United Nations (UN) makes a claim about the rights of children with disabilities:

“States parties recognise that a mentally or physically disabled child should enjoy a full and decent life.....and facilitate the child’s active participation in the community” Article 23, Convention on the Rights of the Child (1990)

Relationships, be they sexual or otherwise, are an important part of a ‘full and decent’ life and the statistics clearly indicate that not many young people with ASD are fulfilling this aspect of life. In a review of studies looking at outcomes for persons with ASD carried out by Howlin and Moss (2012), it was found that where data was available, only 15% of ASD participants reported ever being in a long-term sexual relationship or to have married. More surprisingly, only a quarter reported having at least one friend.

A study by Gilmour et al (2012) indicates young people with ASD do show an interest in relationships and sex, yet they are provided with less RSE and have less sexual knowledge (Stokes and Kaur, 2012) and engage in fewer sexual behaviours (Mehzabin and Stokes,
than their typically developing peers. Koller (2000) cites societal barriers as having played a role in this unbalanced approach to delivering RSE.

The World Health Organisation (2017) also recognises this growing need to promote the best health and well-being for all persons with ASD. Ballan, (2012) outlines the right of all individuals with disabilities to education about sexuality and sexual and reproductive health. For CYP with ASD, proper support and knowledge can see them develop into adolescence and adulthood with the ability to form and maintain healthy, mature sexual relationships. The United Nations Enable (2011, also cited in Ballan 2012) addresses these rights by the endorsement of the Convention on the Rights of Persons with Disabilities in 99 countries with sexual and reproductive health and reproductive rights being addressed explicitly in Articles 23 and 25.

There is consensus in the literature about the need for a programme of RSE to be delivered to young people with ASD. Many studies also point to parents as being best placed to deliver this curriculum to their children. However, difficulties arise regarding exactly ‘what’ to deliver, ‘how’ to deliver it and ‘when’ to do so. The answers to these questions should come from the young people themselves and this is what Hannah and Stagg (2016) tried to establish.

In her book, “Sexuality and Relationship Education for Children and Adolescents with Autism Spectrum Disorders” (highly acclaimed by Furze, 2015), Hartman (2014) professes to reviewing all of the research in this area between the period 1990 to 2012, and outlines a number of shortcomings, many of which are also noted in this literature review.
Most noteworthy was that most of the data gained in studies came from parents and professionals (with a few exceptions, such as Hannah and Stagg, 2016). Additionally, sample sizes tended to be quite small with the largest in this review as N=131. This was mostly down to most studies being qualitative in nature which accounts for the small sample sizes. The largest sample size was attributed to a quantitative study.

A noticeable gap in the literature was the role of teaching staff in delivering RSE to CYP with ASD in mainstream settings. In particular, the self-efficacy of mainstream staff in delivering this curriculum. This is particularly of importance given the reformed statutory guidance published in a press release from the Department for Education (2017) following consultation and amendments to the Children and Social Work Bill due to come into place in 2019/20. These propose that RSE will be compulsory in all schools in England and that all primary schools will teach ‘Relationship Education’ while secondary schools will teach ‘Relationships and Sex Education’ with a central focus on ‘building healthy relationships and staying safe’. It is hoped that this new curriculum will address the increasing risks to children in an era of online pornography, sexting and the like, and will focus not only on RSE, as it did before, but also include mental well-being, resilience, consent and staying safe online.

Also worth mentioning is that studies conducted so far preside mostly within the health and/or social work domain: for example, social work in health; mental health nursing; psychiatry and paediatrics. There was not much from a psychology perspective and certainly not from that of educational psychology, but there is so much Educational Psychologists (EPs) can offer in this area. Working directly with young people and their families and staff
at school, EPs are well positioned to address the RSE needs of young people with ASD in mainstream schools. Mackay (2011) illuminates the potentials of the EP role:

“In terms of training, they (educational psychologists) are the most generic psychologists with more postgraduate training time devoted to the child and adolescent sphere than for any other branch of psychology. In terms of role, they are the most contextualised working across the domains of home, school and community. In terms of background, their knowledge of educational settings is unparalleled.”

Mackay, 2011, p. 11

2.7 Contributions of the current study to the Literature

Research indicates that parents are best placed for delivering RSE to their children (Holmes et al., 2016). However, the research has also demonstrated that parents are not always aware, skilled or have knowledge in this area (Nichols and Blakeley-Smith, 2010; Ballan, 2012). Additionally, as more and more high functioning ASD pupils attend mainstream school, coupled with the onset of the new government legislation in 2019/20, the job of RSE is becoming part of the remit of school staff.

The new legislation will see changes to the title of the subject first of all with the name changing from ‘sex education’ to ‘Relationship and Sex Education’, and will place more of an emphasis on the ‘relationship’ aspect. This will begin at Primary school with the ‘sex’ element to be introduced at secondary school. The new curriculum will also cater to changes in society, specifically, the influence/impact of social media and includes gender
identity topics covering lesbian, gay, bisexual, transgendered, and queer (or questioning- LGBTQ (Oxford Dictionary of English).

In light of this, the present study seeks to explore the current situation within one local authority (LA) in the East Midlands area of England by means of a case study approach. The researcher wanted to explore how RSE is currently being addressed for those young people who are diagnosed with ASD and attending a mainstream setting, so with average to high functioning autism. The researcher will explore the topic from various perspectives within the LA. It will look at the views of parents and young people with a diagnosis of ASD within this particular LA and will go further to address one limitation of past studies by considering the views of staff in mainstream settings who work closely with young people with ASD and who are tasked with, or will be tasked with, delivering the RSE curriculum when the new legislation comes into effect in the near future. It is also of interest to the researcher to obtain the views of educational psychologists working within the LA and explore their perception of the role for them within this area. Within this particular LA, the Autism Outreach Service (AOS) has a prominent role in dealing with all things ASD so it seemed only logical that the study involves them and their views on the topic as well.

This study hopes to bring together the viewpoints of these five different interest groups and discover how the RSE curriculum has been delivered thus far to young people with ASD, within the mainstream context. In so doing, it will also explore what barriers may be present, if any, that could potentially impede effective delivery of this curriculum. To this end, the following research questions (RQ) have been developed:
RQ1: How do the thoughts and views of different interest groups within one Local Authority of the Midlands in the UK inform the delivery/non-delivery of the current RSE curriculum to young people diagnosed with ASD attending mainstream settings?

- Research Sub-questions (RSQ):
  
  o RSQ1.1: ‘How do the views of staff within the local authority affect delivery/non-delivery of the RSE curriculum to young people with a diagnosis of ASD in a mainstream setting?’
  
  o RSQ1.2: ‘How do the views of parents within the local authority affect delivery/non-delivery of the RSE curriculum to their young people with a diagnosis of ASD in a mainstream setting?’
  
  o RSQ1.3: ‘How do the views of young people with ASD in mainstream settings within the local authority affect the delivery/non-delivery of the RSE curriculum?’
  
  o RSQ1.4: ‘How do the views of the educational psychologists within the local authority impact their role with regards to delivering the curriculum of RSE to young people with a diagnosis of ASD?’
  
  o RSQ1.5: ‘How do the views of the Autism Outreach Team within the local authority impact their role with regards to delivering the curriculum of RSE to pupils with a diagnosis of ASD in a mainstream setting?’
RQ2: ‘What barriers might exist to the delivery of RSE for young people with ASD in mainstream settings within this local authority?’

It is hoped that this research will contribute to the development of a RSE curriculum for young people with an ASD diagnosis in mainstream settings in this local authority and perhaps further afield, that is tailored to suit this group of pupils, not only in its content, but also in its delivery.
CHAPTER 3: METHODOLOGY

3.1 Introduction

The current study adopts a case study approach with a mixed methods design, but with an emphasis on qualitative including the use of focus groups and questionnaires, thematic analysis and descriptive statistics.

This chapter describes in some detail exactly how the research was developed and includes a description of what happened in the process of conducting the study, in other words, it details ‘how’ the study was done. It outlines the theoretical perspectives within which the study sits and also gives the philosophical position of the researcher and consequently the research. Rationales for the use of a case study approach and focus groups are given as well as a rational for participant choice. A Pilot study was used and this is also discussed, though briefly, with a statement on how this informed the actual study. The collection of data is detailed as well as an outline of the analysis technique used.

3.2 Theoretical perspectives

3.2.1 Bronfenbrenner’s ecological systems theory

Bronfenbrenner’s ecological systems theory (Bronfenbrenner, 1994) refers to the interactive nature of various factors in a child/young person’s environment and the influence these can have on the child/young person’s development. Bronfenbrenner saw the environment as a context for a child’s development in that it provides an ecological
system within which the child operates, which is important to understanding the child’s development. For Bronfenbrenner, this ‘ecological system’ consisted firstly of a microsystem which included the child’s immediate environment, made up of family, school, nursery, peer group or church. Next is the mesosystem which encompasses linkages between the different microsystems, so between family and school, peer group and family, family and church and so on. It is a system of microsystems. The exosystem goes a step further and involves processes taking place between settings that are outside of the child’s remit but have an impact on him/her nevertheless and include systems such as the neighbourhood, the community and the extended family. At the macrosystem level is the cultural patterns and values, political and economic systems that present resources, opportunities or hazards to the child. Bronfenbrenner (1994, p.40) describes it as “a societal blue-print for a particular culture or subculture”. It refers to specific social features that could impact on the child’s microsystem. Finally, the chronosystem looks at the impact of change or consistency over time. This may include change in financial circumstances, country of residence, family structure and so on.

Figure 1 shows a simple diagrammatic representation of the model.
It is clear then that different systems can impact on the development of the child and/or young person and their understanding of the world around them. Taking Bronfenbrenner’s (1994) theory into consideration, the researcher wanted to explore how the different systems around the young person diagnosed with ASD were impacting on their development of relationship skills in the first instance, and consequently their understanding of sexual relationships and interactions. The research would explore influences within the micro, meso and exo systems (such as family, school, local authority, culture and media) and the interrelationship between these and how they impact on the continued development of the relationship and sex education of the young person diagnosed with ASD.
3.2.2 Theory of Reasoned Action (1980)

Ajzen and Fishbein (1980) developed the Theory of Reasoned Action as a way of explaining how a person’s attitude may influence their resultant behaviour. Unlike previous theories that were concerned with attitudes and attempts to predict attitudes, the theory of Reasoned Action considers factors that may prevent one from carrying out an action and so proposes to predict behavioural ‘intention’. In doing so, it uses behaviour as well as ‘norms’ to try to explain the link between attitude and behaviour.

This research will uncover the attitudes of different interest groups – parents, teachers, autism outreach staff, educational psychologists and young people diagnosed with ASD - towards the topic of RSE first of all, and then towards how it is delivered to pupils with an ASD diagnosis in mainstream settings. The research will explore what effect these attitudes might have on the behaviour of persons in these various groups, particularly as it applies to the delivery of this curriculum. It might be that some may be comfortable and willing to deliver this curriculum while others may still consider this a ‘taboo’ subject and prefer not to have much to do with it. Still others may be alright with it but find the explicitness required for the ASD cohort to be uncomfortable. It is hoped that changing attitudes about how we think of sex and sexuality, particularly as it relates to those with ASD, could impact positively on the behaviour of those tasked with delivering this curriculum.
3.3 Philosophical position: Critical realist

Critical realism, pioneered by British philosopher Roy Bhasker in 1975 (Archer et al. 1998) is a relatively new slant to ontological and epistemological issues (Easton, 2009) that uses ‘causal’ language to make sense of the world. Realists see the world as existing whether we are aware of it or not. There is the assumption that there is a real world, but there is no way that this can ever be proved or disproved. Relativists on the other hand, refute this claim and see no reality existing outside of the language used to describe it. This language is constantly changing and making the ‘truth’ to be non-existent and fallible. This then implies that scientific research is completely useless (Danermark et al., 2002, p.17) as there is no ‘truth’ that exists.

Critical realism bears these considerations in mind and maintains that reality does exist and that while some knowledge of it may be fallible, not all is. Critical realists assume a ‘transcendental realist ontology, an eclectic realist interpretivist epistemology’ (Easton, 2009, p.119) and are positioned somewhere in the middle of a spectrum which ranges from realist at one end, to social constructionist at the other. Critical realists accept that there are multiple realities ‘shaped by social, political, cultural, economic, ethnic, gender disability and other values’ (Mertens, 2010, p.11), but also acknowledging the role and importance of the subjective human individual in constructing their own version of reality.

The researcher also positioned herself within the ‘transformative paradigm’ (Mertens 2010) which emphasises a focus on human rights, social justice and respect for cultural norms while conducting research. It resonated with the researcher’s ontology and epistemology in
that it assumes one reality but multiple ‘opinions’ of it, and tries to challenge thinking about whose version should be considered privileged/wrong within a particular context and the factors that lead us to accept one version over another, factors such as race, religion, gender and in this case, disability.

Situated as a critical realist and operating within the ‘transformative’ paradigm which supports the ‘pursuit of social justice and the furtherance of human rights’ (Mertens, 2012, p.2), the researcher hoped to pay attention to voice: voice of parents, staff, professionals and most importantly, the voice of the young people at the heart of this discussion.

Critical realism is seen as a perfect companion for case study research (Easton, 2009) as it involves thoughtful consideration being given to understanding particular phenomena.

3.4 Research Design

3.4.1 Use of a Case study

Yin (2018) describes three purposes of research: explanatory, exploratory and descriptive. The purpose of the research will determine the way in which the research is conducted - the method. Usually the research question gives a good clue as to what purpose the research serves. For example, a ‘What?’ question usually means the research will be exploratory in nature, while ‘How?’ and ‘Why?’ questions suggest explanatory research. The chosen method must then be relevant to the question being asked and at times more than one method may be appropriate and can be used within one study. For example, an experiment could be used within a case study, or a case study within a survey. While methods are not
mutually exclusive of each other, there are situations where a particular method may have a distinct advantage over another and naturally lend itself to a particular research question.

Yin (2018; 1994) identifies the case study as an ideal design for answering questions like ‘how’ or ‘why’ as these questions focus on operational processes over time. Yin goes on to explain that the case study is also ideal for observing phenomena in a real life context and studying a ‘contemporary event’. A ‘contemporary event’ is seen as a ‘fluid rendition of the recent past and the present, not just the present’ (Yin, 2018, p.12). In other words, the focus is on what has been happening over a period of time including the present. The case study design has the unique ability of dealing with evidence from more than one source, in this study, from different interest groups.

The current research has a research question of ‘How do the thoughts and views of various interest groups within one local authority of the Midlands UK impact delivery of RSE to young people with a diagnosis of ASD, attending mainstream settings?’ and so a case study design was selected in response to the question ‘how?’ and because the researcher wants to focus on what has been happening over time.

A further justification for the case study approach used in this particular study is that it will help to control the study given the researcher’s time constraints. The case study approach limits the study to a particular geographical location within the Midlands UK, and in doing so it creates natural limits in terms of who would be involved in the study itself and makes it more manageable for the researcher especially given the ‘multi-informant approach to data collection’ employed.
Yin (2018) advocates that an initial requirement of case study research is to identify/define the ‘case’. In this study, the case was defined as a phenomenon to be studied – **Relationship and sex education (RSE)**. Once the case was defined, the boundaries of the case needed to be established. The case was first bounded by the group to which it applied, that is, those young people with a diagnosis of ASD attending mainstream schools, within the further boundary of the geographical area covered by the local authority. Added to this, the case was further bounded by the organizations/people whom the researcher felt had a responsibility for delivering RSE within this local authority – parents, school staff, Autism outreach service, educational psychologists.

An initial theory was developed, as recommended by Yin (2018) as a way of providing a “blueprint” for the study, telling us where we should look. The theoretical statement for this study was as follows: **The case study will show that the thoughts and views of the different adult interest groups within the local authority are either preventing or facilitating the successful implementation of RSE to young persons with ASD in mainstream schools. It will also show how to address these barriers to bring about change.**

The first theoretical position is taken based on the researcher’s own personal experience working in a secondary school where some members of staff wanted to veer away from curriculum modifications for this group as they found the material too ‘uncomfortable’ due to its explicit nature. The second position (facilitating successful implementation) is taken based on empirical literature and in the hope that the situation would be positive for most.
The main source of evidence gathered was via qualitative data obtained from focus groups (and individual interviews) made up of different interest groups related to the case. It was thought that using qualitative data would give a better understanding of the complexity of the issues that may be relevant to this case. It also allowed for various participants to give meaning to their constructs and facilitated unearthing of unique and particular meanings.

3.4.2 Use of Focus groups

Focus groups were considered as an alternative to individual interviews as it was felt that it was a more efficient method for gaining multiple views (Krueger and Casey, 2015) within each particular interest group. The nature of the topic also gave some bearing to the use of focus groups as the researcher felt that participants may be less willing to discuss relationships and sex education, particularly the young people, if interviews were 1:1. It was felt that focus groups would give a sense of security in numbers (Bloor et al., 2001) and as we know from Social Learning Theory (Bandura, 1977) they can create modelling and lead to members of the group divulging more information than they would if interviewed alone. Other benefits of using focus groups for this study included the possibility of snowballing (Bloor et al., 2001) as topics arise and reactions to these lead to reactions from others in the group, as well as spontaneity (Bloor et al., 2001) which could give rise to valuable information being gained. Additionally, if someone withdrew from the study, the researcher had other participants within the group so that the effect of a withdrawal would not have too great an impact on the overall study. The use of focus groups also meant that the interviewer was not in a position of power and so the power dynamics usually involved in researcher/participant interactions was reduced.
Individual interviews were considered but the researcher was keen to gain the views of more than just one parent, or one pupil for example, and the time constraints meant that using focus groups allowed for multiple views to be obtained within a shorter time frame, which it was felt would give a much more comprehensive account of what was happening within the local authority. It is appreciated that using individual interviews may have meant that participants may have felt more at ease and be willing to share more and have more time to do so. However, the researcher felt that given the sensitivity of the topic, participants might have felt more comfortable within a group.

There are limitations to the use of focus groups (Krueger and Casey, 2015) such as having dominant voices ‘take over’ the group at the expense of other quieter members of the group. To compensate for this the researcher at times directed questions to particular members to ensure that everyone was heard. There is also the possibility of creating a homogeneous group where everyone thinks alike. To compensate for this, the researcher tried, as far as possible, to gain participants from different demographics within the staff group and the parent group for example.

There were also concerns regarding the analysis of such rich data which could have proven to be problematic especially when transcribing so many voices. Despite all this, the researcher felt that the advantages of using focus groups, coupled with the nature of the topic, made it an ideal choice for this research.
Kruger and Casey (2015) suggest that focus groups should be 5 – 8 participants in size. The current research aimed for groups of 6 participants as 6 was considered a good number to make the group large enough to allow for some diversity of thoughts/views yet small enough for everyone to have a voice.

Notwithstanding the decision to use focus groups as opposed to individual interviews, the researcher encountered much difficulty in trying to gather a group of teaching staff due to their time constraints, staff absenteeism and work demands. In the end, the decision had to be made to collect data from this group individually or else risk not getting staff views at all.

3.5 Participant Sample

The current study, like prevalent studies in this field, had a relatively small sample size. This was due in part to it being a case study within one local authority and thus it was restricted to the thoughts and views of those within this authority alone. The sample size was additionally restricted by the qualitative nature in which data was gathered, that is, through focus groups and the fact that purposeful sampling was used. Purposeful sampling, also known as ‘judgement sampling’ is the most common sampling technique in qualitative research (Marshall 1996). It uses selection based on the researcher’s judgement of typicality or interest (Robson, 2002) and identifies participants with specific knowledge or experience of the phenomenon under observation. It differs from representative sampling which has the ultimate aim of reflecting the wider population.
Purposeful sampling is particularly important when engaging in case study research (Willig, 2001) as participants need to be carefully selected to match the focus of the research, in this case, a detailed exploration of relationship and sex education for young people with ASD in mainstream settings in one local authority. With this in mind, specific participant groups were targeted whom the researcher felt had responsibility in some way for delivering, or ensuring delivery, of this curriculum to young people with a diagnosis of ASD. As such, participant groups included: Parents, Staff, Autism Outreach staff and Educational Psychologists. The researcher was also keen to capture the voice of the young people themselves diagnosed with ASD and so they were included to obtain their views on the subject.

Pre-conceived questions used to generate discussion during the focus groups, were influenced by previous research and also based on additional information the researcher wished to discover. Consideration was also given to Yin’s (2018, p.29) statement: “The more a case study contains specific questions and propositions, the more it will stay within feasible limits”. Some questions, such as “What do you understand by the term ‘Relationship and Sex Education’?”, was the same for all groups to allow for comparison across group participants.

3.6 Pilot Study

It was decided to conduct the pilot study with the pupil group as this group had the potential to be most problematic (and it certainly was). After initially thinking that participants could be sourced from the many after school clubs advertised by the local
authority, the reality was that these clubs either no longer existed, or that the members did not meet the criteria for this study. This was a source of delay in getting started and some minor adjustments had to be made for this particular group.

A pilot study was eventually conducted in September 2018, in two parts, with a young man aged 14, anonymously called ‘John’, who had a diagnosis of Autism. I had an initial discussion with John and explained what the study was about and how it was to be conducted and sought his views on the kinds of questions to ask as well as exactly how might be best to get pupils to engage with me and the topic. Based on this conversation, it was decided to first engage pupils in a questionnaire (See appendix 5), as a way of gaining their confidence and trust as well as gathering some more views of the topic. The questionnaire was developed based on information gathered from previous studies as well as the researcher’s own previous experience of delivering RSE to secondary school pupils some of whom were diagnosed with ASD. Following the questionnaire stage, only those who were willing to participate further would go on to form a focus group. The questionnaire served a two-fold purpose of not only gaining willing participants, but also providing additional data that would go on to contribute to pupil views which, for the researcher, would add significant value in meeting the research aims, as giving voice to these young people was of substantial significance to the researcher.

Furthermore, John indicated some hesitation about forming a group with pupils from another school whom he did not know, which was understandable given the nature of ASD and its impact on social communication and interaction. So it was decided that there would be small focus groups of pupils from the same school. If possible, given time constraints,
2/3 schools from around the county would be approached to get an idea of what was happening within the local authority. In the end, the researcher was only able to find one school with enough pupils matching the criteria and willing to participate in the study within the given timeframe.

3.7 Participant groups

3.7.1 The Pupil participant group

Obtaining the views of the young people who are on the receiving end of this curriculum was very important to the researcher as there was a desire to give ‘voice’ in the research to this particular group. It was hoped that by doing so, necessary adjustments could be made to the curriculum itself as well as the way in which it is delivered.

For the pupil group the researcher wanted to access pupils aged 16 -25 years for a number of reasons. Firstly, at this age they should be able to give their own informed consent to participate in the study. Secondly, the nature of the topic and the research required a more mature attitude and some reflection on what had transpired for these pupils throughout their time at school. It was felt that this could be achieved with an older age group. Thirdly, this was an age group recently added to the Special Educational Need and Disabilities (SEND) Code of Practice (2014) and for whom this topic was quite relevant and yet underexplored in the literature. As a matter of fact, pupil views did not feature highly in the literature at all, with only a few recent studies exploring this aspect (e.g. Hannah and Stagg,
2016), and even so, it was more to do with personal sexuality and less to do with the RSE curriculum and how this was delivered.

It was hoped that participants would be accessed from after school clubs on offer around the county. However, this did not materialise and the researcher had to source participants from different schools. As a result, there were many ‘gatekeepers’ to get by with consent having to be sought from schools as well as parents (Appendix 7). In the end, only one school followed through with participation in the allotted timescale and the researcher had to undergo Safeguarding training with a school’s Designated Safeguarding Lead before being allowed to conduct the research. Additionally, participants who took part in the study were younger than first anticipated and ranged in ages from 13 to 16 (Year 9 to Year 11), which still served the purposes of the study.

Following receipt of consent forms from parents, five pupils who met the age and diagnosis criteria for the study completed questionnaires during one of the pre-visits to the school (see Appendix 6 for results). On this visit the research and its aims were explained to the pupils and opportunity given for questions to be asked. Of this five, four amazing young people agreed to participate in the focus group discussion at a later date. They were accompanied by a Teaching Assistant on both occasions as a condition by the school for allowing me to conduct the research. The teaching assistant provided some support for the pupils by way of a familiar face given the nature of their disability.

The questions used to generate discussion (Appendix 13) during the semi-structured focus group included:
1. What do you understand by the term ‘Relationship and Sex education’?

2. Do you feel this is something that should be taught at school? Why so?

3. Have you received/are you receiving this education at school? Anywhere else?

4. Have you ever used the internet to find information about sexual issues? What did you learn/want to discover?

5. Do you believe you have been given the right tools and information to go on to have successful relationships?

6. Is there anything you feel you have not been prepared for? What could be done to prepare you better?

This focus group lasted for forty minutes and participants were debriefed at the end. No participant raised concern and none was reported to me when I contacted the school following the focus group.

**Reflection:** There were some technical difficulties at the start of this focus groups which meant that proceedings had to be stopped and the questioning restarted. This however, proved to be quite beneficial as it served to provide an icebreaker and made the group much more relaxed in my presence as they found it quite funny that I ‘messed up’ with the recording. Following the drawback, they became much more vocal and forthright with their contributions which worked in my favour (and theirs).
Group demographics are shown in Table 1 below:

**Table 1: Pupil Group demographics**

<table>
<thead>
<tr>
<th>Pseudo Name</th>
<th>Gender</th>
<th>Age</th>
<th>Special Educational Need</th>
</tr>
</thead>
<tbody>
<tr>
<td>Stan</td>
<td>Male</td>
<td>16</td>
<td>ASD diagnosis</td>
</tr>
<tr>
<td>Ron</td>
<td>Male</td>
<td>13</td>
<td>ASD diagnosis</td>
</tr>
<tr>
<td>Edward</td>
<td>Male</td>
<td>15</td>
<td>ASD diagnosis</td>
</tr>
<tr>
<td>Susan</td>
<td>Female</td>
<td>14</td>
<td>ASD diagnosis</td>
</tr>
</tbody>
</table>

A full transcript of this focus group is provided in Appendix 14

3.7.2 The Parent participant group

Within this local authority, The Autism Outreach Service (AOS) offered support to parents and conducted meetings with this group on a regular basis. Participants for this interest group were sourced via e-mail to the group and there was initial interest from 3 parents. Information sheets (Appendix 8) and consent forms (Appendix 10) were sent in advance by email to save on time when we met. An attempt was made to source a mixed gender grouping as previous studies tended to have predominantly female parents which it was felt impacted on their approach to the topic, particularly if their young person was male, which was usually the case as found in previous research. This group consisted of five parents of children with ASD attending mainstream schools and ranging in ages from 6 years to 21 years. Their children all attended different schools and parents were not related to any of the pupils in the pupil participant group. It was felt that inviting parents of the pupil
participants would only contribute to the picture in that one area of the county and the research aimed to discover what was taking place more widely throughout the county. As a matter of fact, parents in this group lived in different locations around the local authority and some distance away from the school of the pupil participants which contributed to the wider picture of what was happening around the local authority.

There was one male parent in the group of five. Time was a constraint as I was ‘piggybacking’ on to their regular meeting with the AOS staff and so I was given only half an hour before their regularly scheduled meeting was due to start. Participants made an effort to arrive earlier than usual to meet with me. An opportunity was given for parents to raise questions/concerns before signing consent forms. The questions used to generate discussion (Appendix 13) were inspired by previous research and included:

1. *What do you understand by the term RSE?*

2. *What are your hopes for the future for your child with respect to sexuality and relationships?*

3. *What are your fears or concerns about your child’s sexuality?*

4. *What do you see as your role as a parent in teaching your child about RSE?*

5. *Are/Were you aware that RSE is being/have been delivered to your child at school? How did you find out?*

6. *Are/were you happy with the way in which RSE is/was delivered to your child?*

7. *Do you think this is a responsibility to be shared by school?*

8. *Were you aware that it becomes compulsory next year? How do you feel about this?*

9. *What topics do you see as being most important/relevant to cover and why?*

Not all questions were asked directly to the groups as some questions were dealt with in answering others.
The focus group was audio recorded and lasted approximately twenty-six minutes. Participants were debriefed at the end. No personal concerns were raised following the focus group.

A full transcript of this focus group is provided in Appendix 15.

3.7.3 The Staff participant group

It was hoped that the staff group could be sourced through SENCo Net meetings hosted by the Senior Educational Psychologists. However, the timings of these meetings were inappropriate for the research timescale so instead the researcher had to contact staff on an individual basis and try to get a group together. This too proved unsuccessful as the researcher realised how pressed for time school staff can be and in the end, three members of staff were interviewed individually. Two of them, a Special Educational Needs and Disability Co-ordinator (SENDCO) and a Teaching Assistant, both female, worked at one high school in one part of the local authority. The other, a past SENDCO and current English teacher, male, worked at another high school in a totally different area within the local authority.

The researcher had hoped to explore how the gender of the staff working with the ASD pupils could flag up interesting dynamics if in opposition to the gender of the pupil they support and how this may impact on their approach to RSE, so having male and female staff
in the group was important to the researcher. Research suggests that there are many more males diagnosed with ASD and school support staff tend to be heavily female based, so this gender variation was important. There was also an effort to include a mix of teaching staff as well as support staff, to allow for different perspectives.

The same questions (Appendix 13) were used to generate discussion in each of the three interviews and were as follows:

1. *What do you understand by the term RSE?*
2. *Do you see a need for this to be taught to YP with ASD?*
3. *Do you see a need for RSE to be tailored to suit the needs of YP with ASD?*
4. *Do you currently teach RSE to pupils with ASD? How is it delivered?*
   - If not, why so?
5. *Do you use an ASD tailored programme? Why/ why not?*
6. *Is it taught in whole class, groups, 1:1? Why?*
7. *How confident do you feel delivering this curriculum? Why/ why not?*
8. *Were you aware that it becomes compulsory next year? How do you feel about this?*
9. *What topics do you see as being most important to cover and why?*

These interviews lasted between 15 and 25 minutes each, following which participants were debriefed. No concerns were raised following interviews.

Full transcripts of each staff interview could be found in Appendix 16.
3.7.4 The Autism Outreach Service (AOS) participant group

The Autism Outreach Service (AOS) was a difficult group to access because they were all quite busy and only visited the office periodically. A time had to be found when most of them were in office at the same time and after some logistical manipulations, the researcher managed to get a few of them together for a half hour slot during their October team meeting. Seven members of the teaching team met for the focus group after being emailed information leaflets (Appendix 8) and consent forms (Appendix 12) through the Head of their service. This was done to save time at the actual meeting though time was given for questions/concerns about the research to be raised and answered at the start of the meeting before the consent forms were signed.

The group was made up of two male and five female experienced teachers of pupils with Autism, all of whom worked for the local authority Autism Outreach Service and covered various schools within the area. The questions (Appendix 13) used to generate discussion were as follows:

1. What do you understand by the term RSE?
2. Do you see a need for this to be taught to YP with ASD?
3. Were you aware that it becomes compulsory next year? How do you feel about this?
4. What topics do you see as being most important to cover and why?
5. How do you think AOS could support schools in this curriculum area? Is there a role for you? If so, what?

This focus group lasted for thirty-one minutes following which participants were debriefed. No concerns were raised following the focus group. The researcher was informed however,
that following the discussion two members of the team felt inspired to set professional
targets around the topic of RSE. The researcher was pleased to acknowledge that she was
already instigating change in thinking and attitudes, even if just raising the profile of the
topic, though the research was not yet complete.

A full transcript of this focus group interview could be found in Appendix 17

### 3.7.5 The EP participant group

Like the AOS participant group, consideration was given to the constraints of time placed on
this group with the demands of commissioned work within the local authority (LA). As such
it was decided to use a time when all EPs were at the office. In this LA, EPs meet on the first
Tuesday of each month to hold team meetings and peer supervision. At the October
meeting, the researcher briefly outlined her research and announced her intentions to hold
a focus group on the day of the November team meeting during the lunch break, suggesting
a ‘working lunch’ approach. Expressions of interest were made by email to the researcher
following which the Information form (Appendix 8) and Consent form (Appendix 9) were
emailed ahead of the focus group date to save on time.

5 EPs/Trainees indicated an interest to participate and took part in the focus group which
lasted about 45minutes. The group was made up of 3 qualified and experienced EPs (1
female and 2 male) and 2 trainees in their 2\textsuperscript{nd} and 3\textsuperscript{rd} year placements respectively (both
female).
**Reflection:** The researcher found it interesting that only the younger EPs elected to participate with some of the older ones commenting that they did not think they had anything to contribute. Is this age bias a reflection of what is happening in society in that those of an older age group still find this topic uncomfortable and perhaps taboo?

The questions (Appendix 13) used to generate discussion included:

1. *What do you understand by the term RSE?*
2. *Do you see a need for this to be taught to YP with ASD?*
3. *Do you see a role for the EP? If so what? If not, why not?*
4. *What topics do you see as being most important to cover and why?*
5. *Were you aware that it becomes compulsory next year? How do you feel about this?*

Participants were debriefed following the focus group and no concerns were raised.

A full transcript of this focus group interview could be found in Appendix 18.

### 3.7.6 The Final Sample

The final sample was made up of volunteers across all participant groups. In the Autism Outreach group, the researcher was given a half hour time slot at one of their team meetings so it could be said that the participants did not ‘volunteer’, however they were free to leave if they did not wish to participate. In all other adult groups, volunteers were recruited via email. Pupils were given the choice of participating in the focus group following completion of a questionnaire.
The demographics of the local authority was such that it was predominantly white, British, middle class and this was reflected across all the participant groups.

3.8 Data collection

3.8.1 Ethical Approval

The study received ethical approval from the Ethics Committee, School of Education, at the University of Sheffield on 23/05/2018 (See Appendix 1). The study followed The British Psychological Society (2014) guidelines for conducting research with human participants – Code of Research Ethics. In addition, the researcher had the approval of the local authority within which the case study was based.

3.8.2 Obtaining consent

The pupil group presented the most challenge in obtaining consent. This was partly because participants had to be sought at schools and posed the challenge of the school as a gatekeeper in the first instance. Once this was achieved, the other challenge was to get parental consent (Appendix 7) to their children’s involvement in the study. Following this was consent from the pupils themselves (Appendices 3 and 4).

Loyd (2012) states that for consent to be valid, it must be given ‘freely’ and without any pressure being placed on the participant. The British Psychological Society (BPS) (2017) sets out in its guidelines that “psychologists who seek to work with children and young people must gain their informed consent”, (BPS, 2017, p.50). Loyd (2012) highlights the particular challenges of obtaining consent from individuals with autism to participate in research given
their impairments in social interaction, social communication and social imagination. Although they share a diagnosis, each individual with autism is part of a heterogeneous group, each one diverse in their presentation.

The researcher had to consider how to fully inform participants about the research and the implications of their participation. An Information Form was presented in a ‘user-friendly’ letter style format with important terms such as ‘confidentiality’, ‘anonymity’ and ‘withdrawal’ explained in a way that was appropriate to the young person with autism yet not overly simplistic to make them feel patronised in any way (See Appendix 2). The Consent Form (Appendices 2/3) was constructed in a similar style and both used a ‘comic sans’ font which is known to appeal to learners with special educational needs. John, the pilot study participant, had also commented that he liked the font as well. Added to this, there were opportunities to ask questions about the research before giving consent as the consent form was read verbatim to participants, 1 item at a time, allowing for discussion of anything that was unclear to any participant.

Harrington et al. (2013) suggests that in gaining consent while doing research with young people with autism, there is the possibility of ‘acquiescence’ where the young person may have agreed out of a feeling of obligation brought about by the power imbalance of the adult researcher or because they are aware that parents have already given consent. As such, the researcher needs to be aware of subtle signs of reluctance to participate such as the level of engagement with the activity. Harrington et al. (2013) suggested the use of a ‘stop card’ which the participant could simply hand to the researcher if they wanted to
withdraw. There was allowance for this with the use of a red card employed in this research, though no one used it.

The adult participants in the other participant groups all completed consent forms (Appendices 9-12) which confirmed their understanding of confidentiality, anonymity and withdrawal from the study. They also had opportunities to ask questions before consenting to take part in the research. It should be noted that due to constraints of time, many of these adult groups were allotted only half an hour. This meant that Information letters and Consent forms had to be emailed to these groups before meeting them to allow time for reading and processing. At the meeting it was asked whether there were any concerns/questions. None were raised, so consent forms were signed in duplicate at the beginning. One participant had printed off her consent form and had it already signed. The right to withdraw from the research at any time was made clear and participants signposted to the researcher’s university email address for contact to exercise this right if need be.

No withdrawals were made.

3.8.3 Collection and handling of data

Data was collected by means of audio recordings of the focus groups. An Olympus recording device with an integrated memory stick was used to audio record the focus group discussions. Recordings were then transferred to the researcher’s password protected laptop and permanently erased from the Olympus device. Transcription of recorded data
followed with pseudo names used to maintain anonymity. Once transcribed, recordings were permanently deleted from the laptop.

There was also some data collected from pupils through preliminary questionnaires (Appendix 5). These were anonymous as there were no names attached. Six of these were completed to varying degrees and the information was collated in a frequency table (see Appendix 6).

3.8.4 Positionality

For each of the focus groups the researcher had given a brief overview of the research and participants freely volunteered to take part. Within all groups participants knew each other but were not aware beforehand of who exactly was going to be in the group. The researcher presented herself as an outsider seeking participant’s insider viewpoint though in some cases it became known later on that the researcher was involved in delivering a similar curriculum in the past to a similar cohort of pupils. It was hoped that appearing to be an outsider would have encouraged an unbiased and open sharing of information.

3.8.5 Safeguarding

Participants were debriefed at the end of their focus group interview session. It was intended that any issues raised or emotional distress would be dealt with appropriately and the participant directed to further support. There were no concerns from the EP, AOS or
staff interest groups. The parent group had numerous questions, not so much about the research itself, but more about where they could go to get help and support for broaching this topic with their own children. Information was shared accordingly based on the researcher’s knowledge of existing literature.

There was potential for emotional issues to be raised within the young persons’ group. However, no such concerns were raised.

All participants had a chance to speak freely and contribute to discussion as the researcher sought the views of all in each participant group. Questions were asked of other participants by participants and it was felt that in all groups there was an atmosphere of comfort and trust.

3.8.6 Confidentiality

Participants were assured in the Information letter about the confidentiality of the contributions they made. For the young people this was explained further. It was stressed that whatever was said in the group had to stay in the group and not be shared with others, however, if something was said that suggested the young person was not safe, then the researcher would have to share that information for their safety.
3.9 Data Analysis

Though not originally planned, the study in the end produced some quantitative data by way of questionnaires, and descriptive statistics were used to report on these.

Qualitative methods of data analysis usually sit within one of two camps: that which is rooted within a particular theoretical or epistemological position such as interpretative phenomenological analysis, and that which is impartial of theory and epistemology and applicable across a range of approaches such as thematic analysis (Clarke and Braun, 2017). The current research adopted a critical realist position which was compatible with thematic analysis and so this was the analytic method of choice for the qualitative data produced from focus group discussions, details of which is given in the next section.

3.10 The Process of Thematic Analysis

3.10.1 What is Thematic Analysis?

Thematic analysis (TA) is described by Clarke and Braun (2017, p.297) and Braun and Clarke, (2006, p.79) as “a method for identifying, analysing, and interpreting patterns of meaning (‘themes’) within qualitative data”.

According to Clarke and Braun (2017), TA offers a sound method, a “tool or technique” by which data could be analysed without theoretical boundaries, rather than a methodology that is bounded by theory. This is not to say that TA is without a theoretical base - ‘atheoretical’, but rather it is versatile, with applicability across various theoretical
perspectives and paradigms (Clarke and Braun, 2017). TA is by far the most common approach to analysing qualitative data and many methodologies employ TA though not explicitly claiming to do so, such as discourse analysis, content analysis and grounded theory (Braun and Clarke, 2006).

3.10.2 Advantages of Thematic Analysis

Braun and Clarke (2006) sees TA as one of the most accessible forms of analysis particularly for those just starting out with qualitative research. It’s relatively simple procedure makes it easy for the beginner qualitative researcher to grasp. Added to this, TA is argued to be a useful method for examining different perspectives, and highlighting similarities and differences (Braun and Clarke, 2006; King, 2004). It also allows large data sets to be summarized in a well-structured manner so that organised reports could be produced (Nowell et al. 2017). Despite these advantages, TA has been subject to much criticism.

3.10.3 Disadvantages of Thematic Analysis

When compared to other qualitative methods, the disadvantages of TA become more apparent, such as the lack of extensive literature on TA when compared with methods such as phenomenology, grounded theory and ethnography for example (Nowell et al. 2017). Added to this is the flexibility of TA which can lead to a lack of consistency and coherence during the development of themes, and has been the subject of heavy criticism. Attride-Stirling, (2001) contests that not knowing exactly how a person went about analysing their data can make it difficult to evaluate the research or compare it with others or even use it
to conduct related projects. For these reasons there needs to be clarity given in research on the process used, with sufficient detail as to how themes were developed.

3.10.3 Why Thematic Analysis

TA, unlike other methods of qualitative analysis, is not “wedded to any pre-existing theoretical framework” (Braun and Clarke, 2006, p.81) and as such it can be used within a realist framework which focuses on experiences and realities of participants, or a constructionist framework which takes into account the impact of discourses on the individual and how these shape their experiences. Likewise, TA can also be a ‘contextualist’ method (Braun and Clarke, 2006), positioned between the extremes of realism and constructionism acknowledging the impact of reality as well as the ways in which individuals make meaning of their experiences within the wider social context. The researcher positions herself here, as a critical realist, and TA lends itself perfectly as a method that “works both to reflect reality and to unpick or unravel the surface of ‘reality’” (Braun and Clarke, 2006, p.81) and as such, it was adopted in this study.

3.10.4 A Step by step guide

This outline as provided by Braun and Clarke (2006) (Table 2) presents a practical and effective procedure for performing TA. It is a recursive process which facilitates movement back and forth through the phases as necessary. Thematic analysis can be a ‘data-driven’ (inductive) or ‘theory –driven’ (deductive) process (Braun and Clarke, 2006). For this study, the data was analysed inductively, and the resultant themes were fully dependent on the
data gathered. An ‘across group’ analysis of the entire data set following phases 1 to 5. This helped to identify relationships in the data across focus groups between themes, to refine themes, and identify exceptions specific to particular groups/data sets.

Table 2: The Process of Thematic Analysis as outlined by Braun and Clarke (2006)

<table>
<thead>
<tr>
<th>Phase</th>
<th>Description of the Process</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Familiarising yourself with your data</td>
<td>Transcribing data (if necessary), reading and rereading the data, noting down initial ideas.</td>
</tr>
<tr>
<td>2. Generating initial codes</td>
<td>Coding interesting features of the transcripts in a systematic fashion across the entire data set, collating data relevant to each code.</td>
</tr>
<tr>
<td>3. Searching for themes</td>
<td>Collating codes into potential themes, gathering all data relevant to each potential theme.</td>
</tr>
<tr>
<td>4. Reviewing themes</td>
<td>Checking if the themes work in relation to the coded extracts (level 1) and the entire data set (level 2), generating a thematic 'map' of the analysis.</td>
</tr>
<tr>
<td>5. Defining and naming themes</td>
<td>Ongoing analysis to refine the specifics of each theme, and the overall story the analysis tells, generating clear definitions and names for each theme.</td>
</tr>
<tr>
<td>6. Producing the report</td>
<td>The final opportunity for analysis. Selection of vivid, compelling extract examples, final analysis of selected extracts, relating back to the analysis of the research question and literature, producing a scholarly report of the analysis.</td>
</tr>
</tbody>
</table>
3.11 Quality Issues – Rigour and Trustworthiness

Issues of quality arise from the use of case studies as well as thematic analysis as an analytical tool. Yin (2018) identifies four critical conditions related to maximising design quality of case studies and ‘trustworthiness’. These include construct validity, internal validity, external validity and reliability.

In this study, comparison of the views of the five different focus groups allowed for triangulation of data, that is, converging evidence collected from different sources, and so increased the construct validity of the research. Triangulation of data also gave rise to certain ‘trends’ or ‘ways of thinking’ within the LA. It also made obvious what barriers exist, if any, to the delivery of this curriculum. Another tactic employed was to have participants review the draft report at the end to give feedback and allow for the researcher to extend and deepen her thoughts and minimise researcher bias. (Yin, 2018; Bloor et al., 2001).

Internal validity usually occurs during the analytic phase of doing a study and in this particular study, was more concerned with making inferences. The researcher tried to avoid this bias by considering rival explanations/interpretations to an occurrence.

As far as external validity is concerned, this is a known “major barrier in doing case studies” (Yin, 2018), as they limit generalisation of the results to the wider public as the research questions they usually seek to answer, hinders this generalisation. This particular study was specific to one particular local authority (with one particular Autism and EP service, pupils
from one school, staff from only two schools) and so its application to other LAs would be arguable, but it is hoped that it would help to inform general thinking and theory about relationship and sex education specifically for young people with an autistic spectrum disorder.

To ensure trustworthiness of the analytical procedure, the following measures were attempted at each phase of analysis as proposed by Nowell et al. (2017):

**Table 3: Establishing Trustworthiness during each phase of Thematic Analysis (based on work by Nowell et al. 2017)**

<table>
<thead>
<tr>
<th>Phases of TA</th>
<th>Means of establishing trustworthiness</th>
</tr>
</thead>
<tbody>
<tr>
<td>Phase 1 – Familiarizing yourself with your data</td>
<td>Prolonged engagement with the data Triangulate different data collection modes (interviews and questionnaires) Document theoretical and reflective thoughts Document thoughts about potential codes/themes Store raw data in well-organized archives Keep records of all data field notes, transcripts, and reflexive journals</td>
</tr>
<tr>
<td>Phase 2 – Generating initial codes</td>
<td>Reflexive journaling Use of a coding framework Audit trail of code generation</td>
</tr>
<tr>
<td>Phase 3 – Searching for themes</td>
<td>Diagramming to make sense of theme connections Keep detailed notes about development and hierarchies of concepts and themes</td>
</tr>
<tr>
<td>Phase 4 – Reviewing themes</td>
<td>Themes and subthemes vetted Test for referential adequacy by returning to the raw data</td>
</tr>
<tr>
<td>Phase 5 – Defining and naming themes</td>
<td>Triangulation Documentation of theme naming</td>
</tr>
<tr>
<td>Phase 6 – Producing the report</td>
<td>Member checking Describing process of coding and analysis in sufficient detail Thick description of context Description of audit trail Report on reasons for theoretical, methodological and analytical choices throughout the entire study</td>
</tr>
</tbody>
</table>

Lastly, the use of case studies and thematic analysis involves analysis of qualitative data which is subject to interpretation which risks reliability as there is much scope for
researcher bias. To help deal with this the researcher tried to make analysis as operational as possible by following the guidelines set out by Braun and Clarke (2006) so that another researcher can follow the same procedures and hopefully produce similar results. Additionally, the researcher practised bracketing (Tufford and Newman, 2010) to mitigate any preconceptions she may have regarding the subject matter and/or the participants.
CHAPTER 4: ANALYSIS OF DATA

4.1 Introduction

Very little quantitative data was obtained and descriptive statistics were used to report on these (see Chapter 5: Findings). This chapter describes in detail the process of thematic analysis as used to analyse the qualitative data produced in the study. To create transparency, the guidelines set out by Braun and Clarke (2006) were adopted and each phase described in detail. Reference is also made to the use of the NVIVO 12 for Mac programme and how some of the data it generated was used to direct thinking around development of themes.

4.2 Transcribing

Following completion of the focus group interviews and individual interviews, the researcher was tasked with transcribing the audio recordings. This was a lengthy process with seven transcripts in total being produced. These were as follows:

- Autism Outreach Service (AOS)
- Parents
- Educational Psychologists (EPs)
- Pupils
- Staff – conducted in 3 separate interviews:
  - SENCO 1
  - SENCO 2
  - Teaching Assistant (TA)
The researcher had hoped to use a software programme to help with this process but in the end decided to transcribe herself manually. This encouraged prolonged engagement with the data (Nowell et al. 2017) enabling the researcher to become very familiar with the data sets and to begin thinking about initial codes and possible themes as similarities began presenting themselves across different transcripts.

Once transcriptions were complete, the researcher was then able to anonymise responses and permanently delete audio recordings ensuring participant confidentiality and anonymity as promised on participant consent forms.

4.3 Generating initial codes

The next step involved coding the data. The researcher used a software programme entitled NVIVO Version 12 for MAC (Nvivo 12) to help with this. The researcher had not used this programme previously so this presented a huge ‘learning curve’ for the researcher.

The first step was to import the transcripts into Nvivo and create some initial codes. While transcribing the researcher had developed some codes which came naturally to the data. These included:

“What is RSE”

“A need to teach RSE”

“What topics to teach”

“How to teach”
These codes were created as “nodes” in Nvivo 12 and applied to the first transcript to be coded, the Autism Outreach Service (AOS). It quickly became clear that a lot more nodes were needed and these were developed accordingly. As more transcripts became coded more and more nodes were created with selections of text within each transcript tagged and coded to an appropriate node. In the end 22 nodes were created and text in the various transcripts coded as shown in Table 4 below.

At this stage the researcher discovered that there was much similarity in the coding across transcripts and as themes began to develop it was decided to analyse the data as a whole rather than as individual participant groups. Not only would this save time, but it also facilitated the researcher’s ability to identify themes across the whole data set sooner.
### Table 4: Initial coding Nodes and transcripts where used

<table>
<thead>
<tr>
<th>Nodes</th>
<th>Transcript</th>
<th>AOS</th>
<th>Parents</th>
<th>EPs</th>
<th>Pupils</th>
<th>SENCO1</th>
<th>SENCO2</th>
<th>TA</th>
<th>Coded texts/ References</th>
</tr>
</thead>
<tbody>
<tr>
<td>A role for the EP</td>
<td></td>
<td></td>
<td></td>
<td>✓</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>21</td>
</tr>
<tr>
<td>A role for staff</td>
<td></td>
<td>✓</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>4</td>
</tr>
<tr>
<td>A role for AOS team</td>
<td></td>
<td>✓</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>12</td>
</tr>
<tr>
<td>Parents role in delivering RSE</td>
<td></td>
<td>✓</td>
<td>✓</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>20</td>
</tr>
<tr>
<td>Parents’ hopes for the future</td>
<td></td>
<td>✓</td>
<td>✓</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>17</td>
</tr>
<tr>
<td>Parents’ views on RSE taught in schools</td>
<td></td>
<td>✓</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>8</td>
</tr>
<tr>
<td>Parents’ fears</td>
<td></td>
<td>✓</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>7</td>
</tr>
<tr>
<td>How is RSE taught</td>
<td></td>
<td></td>
<td></td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>41</td>
</tr>
<tr>
<td>Programmes followed</td>
<td></td>
<td>✓</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>✓</td>
<td>✓</td>
<td>12</td>
</tr>
<tr>
<td>Practical considerations</td>
<td></td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td></td>
<td>✓</td>
<td></td>
<td>✓</td>
<td>46</td>
</tr>
<tr>
<td>Familiarity between adults and pupils</td>
<td></td>
<td></td>
<td></td>
<td>✓</td>
<td>✓</td>
<td></td>
<td></td>
<td>✓</td>
<td>4</td>
</tr>
<tr>
<td>Changes over time</td>
<td></td>
<td></td>
<td></td>
<td>✓</td>
<td></td>
<td></td>
<td></td>
<td>✓</td>
<td>4</td>
</tr>
<tr>
<td>Why there is a need to teach RSE</td>
<td></td>
<td></td>
<td></td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>40</td>
</tr>
<tr>
<td>Cross curricular links</td>
<td></td>
<td>✓</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>✓</td>
<td>✓</td>
<td>3</td>
</tr>
<tr>
<td>When to teach RSE</td>
<td></td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td></td>
<td></td>
<td>✓</td>
<td>30</td>
</tr>
<tr>
<td>Gender matters</td>
<td></td>
<td></td>
<td></td>
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4.4 Searching for Themes

The next step for the researcher was to try to find relationships in the data using features available in the Nvivo 12 programme. First a ‘word frequency’ query was conducted to explore the top 100 words used in the data. This produced a word cloud (See Appendix 20) which helped to identify possible ‘key’ words used in the data and got the researcher to start thinking about what

The researcher then completed a ‘text search’ in the “Query” feature of Nvivo 12 and discovered that the words ‘parents’, ‘relationships’ and ‘school’ produced many links within the data (See appendix 21). This suggested that much was said about these words or involving these words. This may have been because of the questions posed by the researcher, or, due to the context of the topic, these were natural occurrences. The data was interrogated further.

The researcher tried to group the nodes together in an attempt to refocus the analysis and think on the broader level of themes (Braun and Clarke, 2006). Nodes were analysed to discover how they may group together to form a possible overarching theme. The researcher also held in mind the importance of ‘school’, ‘parents’ and ‘relationships’ as discovered from the text search. In addition, the data were explored to see which nodes were coded the most in the data and Nvivo produced a chart of this which was very helpful in narrowing down nodes into possible themes. Initial themes began to develop as shown in
Figure 6 below:

**Figure 2: Development of initial themes by number of coding references**

With all this in mind, an initial thematic map began to develop with five overarching themes and some sub-themes within them. Figure 9 illustrates further.

**Figure 3: Initial thematic map showing 5 main themes**
4.5 Reviewing themes

The researcher then spent some time thinking about the initial themes and revisiting the coded data set. The original research questions were also considered and it was found that there were common features across all groups. These were:

- They all reiterated the importance of teaching RSE to this particular cohort
- They all had a good understanding of RSE
- They all felt that they had a role to play in delivery of this curriculum

In terms of ‘barriers’, there was little data coded in support of this.

The initial five themes (Figure 7) were narrowed to:

- Important to teach RSE – Relevance
- Understanding of RSE
- Everyone’s business

Further thought was then given to internal homogeneity and external heterogeneity of the themes, a criteria for judging categories proposed by Patton (1990) and cited in Braun and Clarke (2006). Data within themes needed to ‘gel’ together in a meaningful way while data between themes needed to be distinct. It was found that there was not a clear distinction between ‘Important to teach – Relevance’ and ‘Understanding of RSE’ as some of the coded data could fit into both themes. It followed that entrenched in having a good understanding of RSE was understanding its relevance and why it was important to teach.
4.6 Defining and renaming themes

The themes were refined further. The names given to the themes were changed to try to capture the essence of what that theme was about. So, ‘Everyone’s business’ was changed to ‘Collective Responsibility’ while ‘Positive perceptions’ was used to encompass the ‘Understanding of RSE’. A final thematic map with two main overarching themes is illustrated below:

**Figure 4: Developed Thematic Map**

```
  Positive perceptions
    Understanding of RSE
      How to teach
      What to teach
      When to teach
      Why teach RSE
  Collective Responsibility
    EP
    AOS
    Staff
    Parents
```
CHAPTER 5: FINDINGS

Results from the qualitative data collected were analysed using thematic analysis across the groups following guidelines by Braun and Clarke (2006). Additionally, a small amount of quantitative data generated from the pupil questionnaires was subject to descriptive statistics. The findings will be discussed below.

5.1 Quantitative findings

Five questionnaires completed by pupils with an ASD diagnosis were returned to the researcher and a tally chart of the results was produced (Appendix 6). It was found that most respondents were unsure of their knowledge of RSE with 3 out of 5 ticking this box while 2 felt secure in their knowledge. Most notable was that all respondents reported to have had lessons at school and know who they can go to if they have questions about RSE. There was mostly agreement for including curriculum topics such as: Making and Keeping friends; Safe sex; contraception; Consent; Dating. Furthermore, there was consensus for teaching to involve discussions, though not necessarily for it to be in small groups or with the same gender teacher or peers.

5.2 Qualitative findings

5.2.1 Findings for research question 1

As described in Chapter 4, the focus group and individual interviews were analysed using thematic analysis across groups and two superordinate themes developed in response to
Research Question 1 ‘How do the thoughts and views of various interest groups within one local authority of the Midlands impact delivery of RSE to young people diagnosed with ASD, attending mainstream settings?’ These were:

- Positive Perceptions
- Collective Responsibility

Each of these themes will be looked at in detail. Quotes are identifiable as P (Parent group), PU (Pupil group), EP (Educational Psychologists group), AOS (Autism Outreach group) and S (Staff which includes the SENDCos and the TA). Pseudo names and line numbers are also given to allow for easy referencing.

5.2.1.1 Positive Perceptions

It was found that the Positive Perceptions of RSE held within groups was grounded in the good understanding all the groups seemed to have of what RSE entailed. There was generally great emphasis placed on the relationship aspect of the curriculum which was missing in previous research, and there was good understanding by parents as well as pupils of the need to develop stable and secure relationships:

“Preparation for school kids, and well kids of any age, so they can have a stable, secure, safe, relationship in the future” (P:Beth, 7-8)

“I really hope Bob can work out some of the intricacies around relationships that I don’t think we are ever educated about” (P:Julia, 87-89)

“to be happy in a respectful trustful relationship” (P:Beth, 123)
“that they prioritise relationships – trust, respect, and that they prioritise friendship. And that you know, they have lots of warm and stable relationships… where they’re giving and receiving, and care, and respect” (P: John, 129-132)

“pretty much relationships is about understanding how different people like think and how to sustain relationships and keep friends and that.” (PU: Ron, 8-9)

“How you get on with pupils, like listening to their needs… and stuff.” (PU: Susan, 22)

The professional groups – EP, AOS and Staff – also expressed a comprehensive understanding of relationships as being meaningful and not limited to a sexual element.

“I’d like to go further and say relationships is also about how individuals relate to each other in terms of, which may over time produce a relationship from the point of view of a family or friend’s perspective.” (AOS: Andrew, 12-14)

“It’s about generating positive relationships, helping children to do that, which is a task in itself” (EP: Ray, 11-12)

“enabling children and young people to develop positive relationships with their peers, with their families as well and also the relationship that they will have with themselves, and how they view themselves, and how that then impacts on their relationships with other people and their interactions and then, you know, how that then feeds into to sexual relationships and what they might look like and … and those interactions.” (EP: Lexi, 63-68)

“It could be anything with anybody, so everyone has a relationship. It could be with a parent, with their friends. It doesn’t have to be intimate.” (S: Alice, 6-8)

There was an understanding across groups that the relationship element was of great importance to the RSE curriculum.

These in depth and comprehensive thoughts and views about RSE then fed into 4 distinct sub-ordinate themes:
5.2.1.1.1 Why teach RSE

Across all groups there was a strong sense that RSE needed to be taught generally but more specifically for young people with ASD because of their neurological difference which manifests itself in the different way in which they process information. A thematic map of this sub theme is illustrated below:

Figure 5: Thematic Map of sub theme ‘Why teach RSE’

Firstly, it was expressed that RSE as a curriculum topic that is needed for all and should be delivered to all, and that pupils with ASD were no different in this respect and needed this topic teaching just as any other pupil.

“All children and young people should be taught about positive relationships and positive sexual relationships and.. and so, for me in that
context, that they, that particular group should be included and part of that.” (EP: Lexi, 95-97)

“I think it’s, you know, it’s part of life and it’s something that they...that every child and young person needs to learn about and I don’t know why you would exclude them from...that population.” (EP: Tess, 101-103)

“I think that cohort would benefit perhaps from additional support but...uhm...like I say I think universally it’s quite a complex area in terms of, there’s a need there for all children and young people” (EP: Ray, 263-265)

Secondly, participants expressed concerns about the vulnerability of young people with ASD particularly if they are not made aware of the expectations of others and the dangers which may pose a threat to their safety and well-being.

“something I’ve become more, uhm...not aware of, but familiar with through casework is the vulnerability of youngsters on the spectrum with grooming, with my kind of post 16 population and maybe younger” (EP: Ben, 234-236)

“so you know what you’re getting into in the future, so you don’t do anything accidentally that could change your entire life” (PU: Ron, 41-43)

“I think they need it. I think when they get older and they go out, they could be real vulnerable.” (S:Alice, 16-17)

“so at that older age they’re obviously quite a vulnerable group and they may be out, out of their parents’...uh... close control, yeah observation as it were, uhm...they’re obviously going to be exposed to quite a lot of things that they may not fully understand or fully in control at that point.” (EP: Ben, 215-218)

“Cause it tends to coincide with what parents want for their children. They want them to thrive and have relationships and not to be vulnerable in those.” (EP: Ray, 261-262)

Linked to the vulnerability aspect is the influence of social media. Many participants felt that social media had a huge role to play in influencing young people’s thinking about RSE
and what they felt was right and acceptable. It was felt that in the current climate, social media had a lot to account for and that it did not always get things right.

“obviously reading social signs through face to face contact is, can be complex enough for youngsters on the spectrum and if you remove that input in addition, that makes it even more complex for our young people. So that’s an even bigger concern and something again that we need to think about relationships and staying safe.” (EP: Ben, 236-240)

“They chat to people and they believe whoever they’re chatting to. They don’t understand that that person says that’s who they are, and put a picture up of who they are but that actually, that could be anybody and they don’t quite get that, that someone could be that deceptive.” (S: Alice, 155-158)

“Well that’s the real danger isn’t it. That actually some of them will look at pornographic films online and think that this is a realistic portrayal of what to expect from sex and it’ll be sort of information gathering and that’s worrying.” (S: Roy, 342-344)

“Well it’s something that I have included and I’ve found in my teaching that there is a wide range of experiences that some of the students had had, where some even in year 8, year 9 had been viewing a lot of internet pornography and just considered it as part of their … their entertainment almost, part of their sexual lives.” (S: Roy, 309-312)

“I think that education needs to think about what children can access outside of school and also, on YouTube for example and various other websites and they need to be quite explicit on whether its ok to be looking at those types of websites because some are harmless so to speak but might not be to all children.” (AOS: Rebecca, 85-88)

Lastly for this sub theme was the need to take into consideration the difference in information processing and the need to make things obvious for young people diagnosed with ASD. More than one group highlighted the social communication difficulties within this cohort and the need to make obvious the nuances of relationships.
“they have a social communication difficulty and therefore would uh, present as more likely to have difficulties in understanding about relationships and sexual sex education.” (AOS: Andrew, 49-51)

“but there should be consideration that young people with autism are less likely to pick up the subtleties that are sometimes taught in the normal approach to teaching sex education and it’s not explicitly taught from the point of view of understanding from another’s person’s perspective.” (AOS: Andrew, 52-56)

“the difference in processing information that obviously that could lead to...is...explaining to a pupil with autism that their relationship with another person might be different from the norm as well.” (AOS: Bob, 61-63)

“from my point of view I’m really glad he’s done this, in this environment, with other children his own age, and he will now not be confused by these words that are banded around the playground. He knows what it means.” (P: Sam, 30-33)

“I think the difference as well is explaining to children with autism, what’s a friendship, what’s a relationship with a family member, what’s a sexual relationship and a relationship with a partner. They’re three very different things that get very blurred for autistics” (S: Carrie, 158-161)

“Yeah and I learned very quickly that actually, when you are delivering a curriculum like that with young people with autism, they would say and ask things that a neuro-typical young person would be too inhibited to.” (S: Roy, 187-189)

One member of the AOS group gave an example of why it was important to make things explicit to this cohort of pupils:

“I’m thinking of an incident where a parent, where her child had sort of access some RSE at school and her understanding was that the age of consent was 16, so at 16 she had to go and find a boyfriend because she had misinterpreted what had been delivered as a key message” (AOS: Lisa, 78-81)
A further example was also shared by a staff member:

We had another young man who, uhm... had uhm... had himself... had inappropriate sexual contact with a younger family member, so that had to be addressed in those lessons, you know, it is essential in order to help to stop that kind of behaviour. (S:Roy, 74-77)

5.2.1.1.2 What to teach

Discussions with the various groups revealed that while all topics within this curriculum were important, certain topics needed to be made more explicit and given more emphasis than others for this particular cohort of pupils as shown below:

Figure 6: Thematic Map of sub-theme ‘What to teach’

Safety was considered a major area to be covered within the curriculum for this cohort given their difficulties with communication and understanding implied meanings. Safety also encompassed internet safety and sexting:

“More like ‘keeping safe’ and you know ‘what’s a healthy relationship’
and ... ’who are, who shouldn’t, stranger awareness’ and that kind of thing” (EP: Tess,227-229)

“obviously reading social signs through face to face contact is, can be complex enough for youngsters on the spectrum and if you remove that input in addition, that makes it even more complex for our young people. So that’s an even bigger concern and something again that we need to think about relationships and staying safe” (EP: Ben,236-240)

“And gaming and how to keep yourself safe online. That’s another thing because they do do a lot of gaming where they chat to people and they believe whoever they’re chatting to.” (S: Alice,154-156)

“I think just the concept of peer pressure and peer expectations. So whether it comes from what some people have seen on YouTube because young people will have different access at home ...“ (AOS:Maxine,109-110)

“including kind of more.. recent patterns of behaviour like sexting” (EP: 8-9)

“I guess there’s a need to ...also make children aware of where they can go to if they need support. And that is part of the teaching as well...who can they go to, what agencies are there, what should they do in a situation where they’re feeling vulnerable, what sort of steps they could take. Giving them strategies to manage their own safety as well and empowering them in that way. I think that’s a really important aspect of it.” (EP: Tess,346-351)

Additionally, the practical aspects of being safe, for example, knowing when and where it was safe to do things like masturbate, were also considered to be important for this cohort.

“from a physical point of view its often things about... when it’s acceptable to expose yourself or who can you be naked around...or... where and when can you be naked or....where and when is it appropriate to masturbate and things like that that I think neuro-typical young people intuitively pick up on .....” (S: Roy,234-237)

“knowing what is acceptable and what isn’t.” (S:Carrie,169)

“I think maybe in sex education things can be very explicit but we still make a lot of assumptions about, you know, where it’s safe to, how we can do things,
who it’s safe to ask. So whether it’s around masturbation, whether it’s around periods, but it’s just being really explicit and therefore what’s within the comfort level of that young person.” (AOS: Lisa, 137-141)

Issues around gender identity was another area thought by many to be important to include in a RSE curriculum for this cohort in particular, as it was thought that there could be confusion around this. One member of the AOS group referred to a young person who experienced difficulties in this area:

“I’ve worked with someone who actually experienced that. And this young person uhm... on the autistic spectrum, believed that they needed to change their sex to become female and two years later, it became much more evident that they were actually gay” (AOS: 294-297)

Discussions also centred around what was happening in the current climate in terms of gender and how important it was to address this with this cohort.

“And I think with the issue of gender identity, culturally you know, what the kind of climate looks like now, actually, we, we need to think about how we’re teaching that to kids. Definitely.” (AOS: Rebecca, 309-311)

“I don’t know in terms of teaching around sexual orientation, uhm... that kind of thing. Like gender, I wonder whether they’re being taught explicitly within school.” (EP: Tess, 85-87)

“I think some of them were curious about how gay people have sexual intercourse and what would be the differences between gay experiences and heterosexual experiences.” (S: Roy, 264-266)

Parents particularly stressed the importance of allowing their children the freedom to explore their gender within different kinds relationships with a knowledge that there’s no ‘right’ or ‘wrong’.

“I suppose just knowing the different kinds of relationships there are and that they are all....fine.” (P: Sam, 147-148)
“We started talking about a little bit, about the kind of feelings and having gay feelings and whatever. I think it really doesn’t matter whatever” (P: Beth, 164-165)

“I just want him to not get fixated with what’s normal and what isn’t normal...” (P: John, 127-128)

“I told him the other day you know, I said men can marry men now as well. Women can marry women. And he said ‘Really?!’ you know, (laughs) I said, ‘yeah’, you know, and I kind of just want this to be kind of normal and for him to be humane, kind of.” (P: Jade, 106-109)

Pupils also expressed a desire to know more in this area:

“We could include more on homosexuality. Like LGBTQ material. This was touched on but not in too much detail.” (PU: Stan, 448-449)

Another area of great concern for parents and professionals alike was that of consent. Much was said of the importance for young people with ASD to understand ‘giving’ consent as well as ‘getting’ consent within the context of RSE. One parent expressed the importance of teaching her son about consent at an early age:

“If someone says no, they mean no immediately and you just need to back off however you’re feeling. This is not about you, this is about the other person and I felt quite pleased that actually we can now, we can transfer that in the future into other things like sexual consent.” (P: Julia, 136-139)

Within the EP group there was talk about the way in which consent was intertwined with language, this being an area of difficulty for the ASD population, and the need to make explicit what consent looks and sounds like.

“I think there’s something as well around language and the way that language links to consent. And...I’m talking more specifically about what you mentioned especially with uh...young women who might by particularly vulnerable to grooming, around the sort of phrases, the sort of language people might use and just...and embedding that more broadly into what consent means and how that relates to your....yeah
the consent that you give to being in the relationship you’re in ...” (EP: Becca,297-302)

“I think that for all young people, consent is a really important uhm...it’s a really important concept when it comes to sex and relationships and I think that a lot of, a lot of what happens around consent is around power, is around control and language is really key in that so I think that, that, again, it’s important for all young people.” (EP: Becca,314-318)

“I think it’s important (teaching about consent) and needed and that kind of thing should be adapted for the ASD population.” (EP: Becca,319-320)

Staff also expressed views about teaching consent within the RSE curriculum to young people:

“Absolutely everything to do with sex and what is acceptable, when it’s ok to do things, when do you stop if you feel forced into doing things” (S:Carrie,170-171)

Within the Pupil group, many of the young people highlighted a lack in the curriculum with regards to teaching the more practical aspects of RSE. While they all appreciated the more obvious aspects of the curriculum being taught, it was felt that they were then left not really knowing how to approach relationships, what to do on a date and so on:

“I feel like we have learnt about like how it all works and stuff, but we haven’t really learnt how to like ... ap-pr-oach it like say....” (PU: Susan,417-418)

“Yeah.... like how to deal with it and stuff” (PU: Susan, 421)

“That’s because they never really teach that side of it. They teach the biology of it.” (PU: Edward,423)

“Yeah I suppose things like just asking a girl when to go on a date with her.” (PU: Edward,138)

“because as well as learning about it, you can’t just like go off and do it.
It’s, it’s gotta get to that point, you can’t just like... And then like how to approach when it does get to the point. It’s going to be awkward like...
Susan > Yeah and how to notice when the other person is like....
Stan > Ready
Susan > Yeah
(PU: Stan/Susan, 139-144)

One pupil participant also indicated a need for teaching to incorporate an element of learning about slangs/abbreviations:

“Generalized talking to people on the phones and just talking to people in general, because nowadays, you start teaching a language because everyone keeps making up new words no one understands. Shortening words on phones, needs to be taught in lessons.” (PU: Edward, 237-240)

Within the EP group, consideration was given to acknowledging that relationships are not perfect and that it’s ok to make mistakes sometimes but that it’s what we do to put it right that counts.

“I think kind of normalising that relationships are complicated and that ...whether you’ve got additional needs or not. They can be very confusing and emotional and...and that’s ok but it’s how we manage it...uhm...and what we can do about that and so acknowledging that relationships are hard work ....and we can perhaps all do things in relationships that may not...that we may regret later or...or what have you, and that we need to repair relationships and how do we do that, how do we go about that” (EP:Lexi,355-360)
5.2.1.3 How to teach

One pupil summed it up nicely when he said: “it’s more like HOW it’s taught instead of WHAT in it is taught”. How RSE is delivered is an important consideration for any RSE programme but particularly so within the ASD cohort and a thematic map of this sub-theme is illustrated.

Figure 7: Thematic Map of sub-theme ‘How to teach’

Consider individual needs

How to teach

Gender matters

Resources

The importance of considering individual needs was highlighted within the professional groups. These groups reported that it was first necessary to think about the pupils’ development and readiness for this learning.

“And also thinking of them in sort of like, emotional development and how that vary and differ and actually at what age and stage they emotionally are. Are they ready to have those conversations and how that changes over time and how it might differ within groups, you know, quite significantly” (EP: Lexi, 78-81)

“I think it should be looked at as very individual and I think that just
because data has shown that certain people may engage at certain ages in sexual relationships, doesn’t mean that all should be.” (AOS: Andrew, 43-45)

“I think it really, it really has to be based on individual needs rather than a blanket approach.” (S: Roy, 60-61)

“I think it depends very much on the needs of the individuals or the cohort of autistic students you have got.” (S: Roy, 42-43)

Parents also felt that detecting readiness was important and that readiness was not always linked to chronological age.

“It’s probably a good time to have a conversation about it. It’s in his mind, he’s telling you that he’s learnt about it, so take the opportunity and tell him now what you want him to know, and use the opportunity really.” (P: Sam, 43-45)

“I don’t feel there is a cut off age at which you should first start the subject. I think it’s a natural part of the language that they hear. And it’s on their mind to a degree, and I think parents just normally want to go with that” (P: John, 67-70)

Individual circumstances of pupils could also dictate where they are in their development of sexual knowledge and their readiness for learning about RSE. One parent described the situation for her 6 year old son:

“so my son is 6, almost 7, and because he’s got an older brother I think we have, have talked about it because the older one has brought things up....”(P: Jade, 52-53)

“So what, what I’m saying is that my 6 year old is in on that conversation. He’s not initiating them, but he’s in on them and I feel really happy with that for the same reason as Beth, you know, you’re kind of drip feeding. He’s picking up little things. And he knows it’s not a taboo subject and I am not phased by those questions.” (P: Jade, 56-60)

In addition to readiness for learning and development, it was also felt that there should be a highly tailored curriculum differentiated to meet the pupil’s ASD needs. Among staff it was
agreed that the RSE curriculum must be made accessible and meaningful to the pupils.

“we make it really tailored to the individual’s needs” (S: Carrie,47)

“And the group that we ran they needed a very, very, very basic approach. The group that’s running now needs something a little bit more detailed. They’re a bit brighter, a little bit more ‘with it’ whereas the previous group we really needed to talk about the basics.” (S:Carrie,48-51)

“There are some individuals we can’t involve, and they may have their sessions sort of on a 1:1 because they wouldn’t cope with the group setting…. And the children like this we tend to give a 1:1 session to.” (S::Carrie,73-75)

Within the AOS team there was agreement that the curriculum should be made to fit the child’s needs as opposed to fitting the child to the curriculum.

“To pick up a programme creates a danger cos: ‘Well here’s a programme, we’ll fit the child around the programme’ whereas I’ve always been where we fit the programme around the particular individual.” (AOS: Andrew,224-226)

EPs too reiterated the importance of differentiating for this curriculum just as is done for any other subject area.

“But you make that judgement call based on your understanding of that child’s ability to cope and access, just like with any other element of the curriculum and school day.” (EP: Ben,118-120)

“So if you make a judgement call based on your knowledge of that child on the spectrum, if they can access the same level, at the same pace, at the same uhm... kind of pitch and uhm... with the same resources, then yeah. Why not teach them with their peer group.” (EP: Ben,115-118)

“like differentiating in an appropriate manner so if, if they’re able to access that at the same level as their peers, then you wouldn’t actually just take them out of the classroom and teach them a different approach.” (EP: Ben,112-114)

Even pupils gave voice to their feelings on RSE being delivered based on the individual needs
or preference:

“I suppose if with your parents you should also do it on your terms. So obviously like, they shouldn’t just come over to you and go “oh we’re going to talk about this now”. It should be your choice.” (PU: Edward, 71-73)

“it depends on the person itself like what they are like” (PU: Stan, 278)

It was felt that matters surrounding the issue of gender may have posed some difficulty when delivering this curriculum, however across groups this did not appear to be too great, a problem. Within the pupil group, the researcher was keen to get their voice in the matter, there was consensus among the male pupil participants to have RSE delivered to the whole group together. It was felt that each gender needed to know about the other.

“Of course it’s easier to teach in a big group plus you can talk to all your mates and stuff there in class about it. You can talk to the other gender about it... just general....” (PU: Edward, 267-269)

“then it will just be the girls are only learning about the girls area of that part when you need to learn about both” (PU: Stan, 367-368)

Some even displayed some indifferece to the matter:

“I would rather just do it. Ok. I don’t really mind either way. I can do it anyway because either way it’s just...you’re learning the same thing really, so it’s no less awkward whether you’re in umm... mixed class, small group or large group, or literal individual.” (PU: Ron, 299-301)

“I find in small groups it’s fine, but big groups it doesn’t make any difference at all.” (PU: Edward, 266-267)

One male pupil participant though considered that the girls tended to be the ones to be more embarrassed by the subject and so consideration should be given to them:

“Actually it would be easier having them split because I find the girls generally get more embarrassed than the boys do about it.” (PU: Edward, 345-346)
The female pupil participant was in agreement and shared that she may prefer to have groups separated by gender:

“Personally, I would find it easier. Like even if, like we still would learn about like... stuff with boys and stuff ....but I would find it easier just with girls because if the boys were there.... I just feel awkward.” (PU: Susan,380-382)

The gender of the staff delivering the curriculum also came under debate within the pupil group and again, surprisingly this was not much of an issue:

“Well I feel like it will be less awkward with a woman, but with a male teacher it would just be like a teacher teaching.” (PU: Susan,392-393)

“Yeah the teachers just act like it doesn’t matter anyway.” (PU: Stan,385)

“I don’t think it really affects.....” (PU: Ron, 384)

For staff delivering the curriculum, matters relating to gender could be dealt with based on the demographics of the group as well as the demographics of the staff available to deliver the curriculum. So at one school where two members of staff were available it was shared by gender with male staff taking male pupils and vice versa.

“the way we used to do it was I take the boys group and she takes the girls group.” (S:Roy,84)

At another school however, the situation was quite different with a female member of staff delivering to an all-boys group as there were no females with an ASD diagnosis at this school and the available/designated member of staff who knew the pupils well enough was female.
“The reason we’ve got a female delivering it is because she is the key worker to a few of them in there. She’s got a very good relationship with them and they feel comfortable with her. She’s also comfortable delivering it. She has questioned whether there needs to be another member of staff in there but when we looked at that, we felt that that would change the trust and dynamics a little bit so she’s happy to carry on.” (S: Carrie,109-113)

There are times when it is necessary to have the same gender staff as pupils and allowances are made for those occasions when a question pops up that would be more aptly answered by a male member of staff:

“However, the head of PSHE (Male teacher) is coming in to talk to the boys about things she can’t answer, so one of the questions was ‘what does a wet dream feel like?’ because there’s a couple of boys who haven’t had one or don’t know that they’ve had one maybe…” (S: Carrie,113-116)

“If he could shed a little more light on it because obviously it’s not something a female could answer. But we’re really, really clear with the children that they can ask anything and we’ll answer anything, obviously within reason.” (S: Carrie,120-122)

When considering the resources to be used, the AOS group seemed quite a handy service for advising schools on available programmes:

“There are so many materials. So we can look at Fiona Spears’ materials. Uh… Lynn Moxon’s materials from ESPA, uhm and there’s whole programmes there that perhaps have not been constructed by ourselves. Uhm… Isabella Hanou’s work uhm, it’s all published through Jessica Kingsley.” (AOS: Andrew,217-220)

“We use a specific programme which was advised by Autism Outreach and I’m trying to think of the name…. It’s a huge folder and it’s very visual. It’s broken down into topics, it’s very clear.” (S: Carrie,38-40)

The AOS group were keen to caution about just using a programme without considering the
fit for the particular individual:

“I’m quite averse about just picking up a programme without...we. we’d send that message to a school where, well it says here’s a programme about autism, here’s a child with autism so therefore... I’d prefer, I’d much prefer to take Fiona Spears’ work, for example which has got some pointers, some ideas and... and... and then moulding it that way.” (AOS: Andrew, 226-230)

At another school, different programmes were used:

“One was from Nottingham City, uhm... and the other one was the Scottish National Autism uh...SRE curriculum. That one was really good I thought. Yeah, I would sort of take bits out of both of them and sometimes make up things of my own depending on the individual need.” (S: Roy, 156-163)

In addition to the programmes used as a guide for teaching, staff also reported using other resources such as various forms of media and visual/hands on resources to make explicit the intricacies of RSE.

“Something else we’ve done actually, we’ve watched clips, appropriate clips from First dates, when men have got it wrong, women have got it wrong and what mistakes they’ve made.” (S: Carrie, 155-157:)

“And it makes it very visual, it’s very practical – we use real objects rather than fake. So, we’ll use a proper condom. Obviously on a fake penis (laughing) That would get a bit awkward! And uhm...contraception, we use actual contraceptive devices” (S: Carrie, 44-47)

Pupils also commented on resources used:

“literal videos of watching stuff” (PU: Stan, 102-103)
5.2.1.1.4 When to teach

A thematic map of the sub theme ‘When to teach’ was developed and is illustrated below:

Figure 8: Thematic Map of sub-theme ‘When to teach’

Within all the groups there was discussion regarding what age/Year group was the most appropriate to start delivering this curriculum. Among the professional groups, there was acknowledgement that the ‘Relationships’ element could be taught from quite a young age:

“this could be kind of a collected view that we feel that the education should start you know, from a very young age” (EP: Lexi, 244-245)

“(I have) other friends that have taught it within Year 1, and things like that, you know, to do with anatomy and that kind of thing and naming things and the appropriate labelling of body parts and things like that. And I think that’s where they start it in terms of that, but then also looking at relationships and boundaries of relationships. Like what’s a safe relationship and who do we have relationships with and I guess looking at it from that aspect.” (EP: Tess, 19-24)

“I think maybe a secondary age is too ... I think it needs to begin ... you know sort of primary age.” (EP: Tess, 225-226)

Parent participants shared that there should be no ‘right’ age to start and that teaching
could begin informally in the home as young as 6 years old:

“I don’t feel there is a cut off age at which you should first start the subject.” (P: John,67-68)

“so my son is 6, almost 7, and because he’s got an older brother I think we have, have talked about it because the older one has brought things up.” (P: Jade 52-53)

Among the pupil participants, the general consensus was that teaching of RSE should begin around Year 6 which is around the time that most of them remember doing sex education for the first time at school.

“I’m reasonably sure they did it fully in Year 6 at that time if I remember correctly.” (PU: Ron,116)

It was felt within this group that Year 6 is a good time to start learning about RSE because of physical development:

“because puberty is what triggers the... like it generally triggers both the desire to do it and also the means to do it within your body and because of learning it then you’ll understand the consequences of doing certain actions in the future which will help prepare you so you know what you’re getting into so you can’t say that I accidentally did this or did that.” (PU: Ron,15-19)

Little was said about relationship education being made explicit to them when they were younger or at primary school, but it was suggested.

“in the younger years and stuff you should do more about like friends and relationships and stuff and when you get into the later years you should do more about like....

Ron > The sexual parts” (PU: Susan/Ron, 219-221)

The researcher really wanted to give voice to the pupil participants in terms of delivery of
this curriculum and so specific reference was made with this participant group regarding the approach to be taken when teaching this curriculum. It was found that views here differed among the pupil participants. One preferred everything to be taught “in one go”, never to be looked at again.

“I think it’s nice to get it all done and dusted in one go because most people find this topic uncomfortable generally, so it would be best to just sweep it all under the rug as soon as possible.” (PU: Ron, 208-210)

“You should, I think you should just include as much as possible because it’s just this one off thing and once you finished it then you can pretty much...if you do it over a long period of time it’s just coming back to it over and over again and if you do it all in one sweep, then it’s a lot more comfortable kind of because you know like, after today it’s over.” (PU: Ron, 197-200)

Most, however, preferred a spiral approach, where little is taught at any one time and the topic is revisited frequently adding to previous knowledge.

“I disagree with your comments though. When you’re in the year 7 you’re at that immature age where you are just going to mess around and not take any of it in. So if you just do it all in one go, all in Year 7, none of it’s been taken in.” (PU: Edward, 212-214)

“A little bit each year but not too long.” (PU: Edward, 216)

“more or less ease into it, instead of like, just go straight into it....yeah” (PU: Stan, 227-228)

“we cover it at certain times. It’s just like I’d rather do a couple of weeks on it every year than we do at school.” (PU: Edward, 148-149)

“I was taught it...(Years)6 and 7... 6 was a curriculum review, 7 was the full topic, but it was more on... like what each body parts does and then I believe year 8, year 9 was going into detail about a different like... consequences, like the diseases you can catch.” (PU: Stan, 166-169)

“So at my old school they did it in year... they did a quick overview of it in year 6, but then they actually went into more detail in Year 7...” (PU: Stan, 107-109)
Staff participants also reiterated the spiral approach as the preferred method used.

“So we do uh… something called a friendship group in Year 7…… Year 8 we do, we just call it sort of social skills and we up it slightly. So we talk in a little more depth, we get children to go off and do things and come back and feed back, you know, ‘did that work? Didn’t it work?’ And these are children who are quite socially isolated.” (S: Carrie, 85-93)

And then in year 9 we deliver the one I was talking about which is not just focused on sex but on the changing ...the way our bodies are changing.” (S: Carrie, 99-101)

One parent also felt that this was the best way and drew an analogy with the teaching of any other subject in general:

“I think little by little is quite good, with a bit more information each time. It’s like anything you learn, you know, you don’t learn French with everything at the beginning. You learn first how to talk about your holidays this way, and then a bit more, and I think sex education is learnt the same honestly.” (P: Beth, 48-51)

5.2.1.2 Collective Responsibility

Figure 9: Thematic Map of super-ordinate theme – Collective Responsibility
This second super-ordinate theme developed, as among all of the adult participant groups it was felt that teaching RSE to young people diagnosed with ASD was the business of everyone and that all had a duty, a responsibility to deliver this curriculum.

**Parents’ role**

Previous research had indicated that this was mainly a role for parents though it was revealed that parents didn’t always know how to go about this or what to teach. The current research found that parents were very much aware of their responsibility in teaching their young person about relationships and sex and were happy to take on this role.

“I feel like it’s a 100% my responsibility. And you know, I feel like I’ve been on it.” (P: Julia, 221)

“I just want it to be embedded into everything. I just want to, I feel, I feel extremely responsible.” (P: Julia 225-226)

“this is up to me” (P: Sam, 262)

“I want it to be more of me” (P: Beth, 257)

“I agree. Yes, as a parent, it’s completely my responsibility.” (P: Julia, 264-265)
As a matter of fact, one parent described how angry her husband was that he wasn’t involved in his son’s first experience of RSE:

“Well NOBODY asked me about this. I am NOT happy. He’s my son. I should be educating him about all this. He’s too young to know.” (P: Sam,28-30)

Pupils also cited a role for parents in delivering RSE:

“Well they kind of....well it’s kind of better coming from your parents cos’ you like know them a lot more and stuff and you understand how they’re trying to like get it through to you. It’s like, it’s like when somebody you don’t know tries to explain it to you it makes you like...question it kind of....” (PU: Susan,58-61)

Parents, while aware that teaching their children about relationships and sex is their responsibility, expressed that they are comfortable to share this with school as long as they are made aware of what is being taught and when it was being taught.

“I think it would be more helpful if they perhaps published what they taught like a personal email or something so we can actually read it and we can go, Ok. And we can pop it into conversation or we can say, ‘Ok, I understand you did this today. Do you want to talk about it? Is there anything you didn’t understand? What about this?’ So it would have been really good from our point of view and I think from my son’s dad’s point of view for him to have known what had been discussed.” (P: Sam,290-295)

“from my point of view I’m really glad he’s done this, in this environment, with other children his own age” (P: Sam, 30-31)

“Just to kick start, for someone to start it off and then I can throw in the things they haven't heard” (P: Jade,288-289)

“Well I was going to say that even if I disagreed with it, I would want it to happen so that we can have an opportunity for me to say 'oh did they think that?' You know some people think...” (P: Julia,285-287)

“It would have been really good from our point of view and I think from
my son’s dad’s point of view for him to have known what had been discussed.” (P: Sam, 293-295)

“I’m slightly concerned about it because I feel being high functioning autistic myself, I haven’t got some of the skills that I want to be able to have my son doing. So I agree. Yes, as a parent, it’s completely my responsibility. But sometimes I worry I’m seeing this from my perspective whereas I can’t see it from a neuro-typical perspective. And sometimes it will be nice to feel that somebody else was there putting some input in.” (P: Julia, 263-267)

“Parents are happy with the whole process. We seek their permission and they send back consent forms saying that they agree.” (S: Carrie, 126-127)

“So I would generally ring up the parents, give them a bit of a gist about, you know, ‘We’ll be covering this kind of thing’ and they would say ‘oh yes please’, usually.” (S: Roy, 102-103)

The AOS group stressed how important it was to keep parents involved and ‘in the know’ particularly with an ASD cohort, to ensure consistency of approach and information across contexts.

“just to say as well that if you’re looking at the curriculum of RSE for young people particularly with autism, then involving parents in that and making sure that they are exactly familiar with what’s being taught so that they can reinforce messages at home. And also address any misconceptions that arise” (AOS: Lisa, 75-78)

“I think the danger is.. with it becoming something that schools take full responsibility for, and legally it has to be delivered to every child, is that you, you.. perhaps do lose an element of working with parents on how they support their children in learning about sex education and I think that’s vital because we want that to be happening, you know, to be reinforced and embedded at home.” (AOS: Rebecca, 263-267)

“so you want to retain that parent partnership as much as you can I think and even more so with children with autism so you know you’re on the same page and you’re putting across the same messages.” (AOS: Rebecca, 269-272)
Within the EP group there was also talk of the involvement of parents and the role they are playing in educating their young people about relationships and sex.

“increasingly recently, parents seem more prepared to have that discussion with me. I don’t know if that’s just a recent thing for myself, but they seem to be prepared for the short and long term in terms of what they want for their child and particularly for children on the spectrum” (EP: Ben,406-409)

Staff role

This was an important group for the researcher as there were no previous studies centred on staff who are tasked with teaching this curriculum and so the researcher was keen to discover how they saw their role within this area. One member of staff who was male, felt that he was probably better suited to teaching a young man about this topic than his mother was, as the pupil had an understanding that he had to listen and obey his teacher so he was keen to follow whatever the teacher said. He didn’t have this with his mother.

“He takes no notice whatsoever of what his mother tells him about matters to do with sex or... nudity in the home or sexualised behaviour in the home, but if I tell him, he listens. ...because I’m a teacher.” (S: Roy,30-36)

There was a feeling of staff being able to fill the gaps that might not be able to be filled at home. So in the above example, there was no ‘father figure’ in the home and so the male member of staff was also able to fill in and provide some guidance for the young male pupil in addition to being an authority figure. Staff are also able to supplement and reinforce knowledge first gained at home and fill in any existing gaps that may exist for pupils.

“I suppose it all depends on how well this has been handled in the family or to what extent the...young person takes notice of what the family say.” (S: Roy28-29)
“it gives them the opportunity to open up about things they want to ask but will feel very embarrassed to ask” (S: Carrie, 43-44)

Additionally, staff felt that they had a role to play in adapting materials to suit the needs of the young person and making the topics more accessible and understandable.

“I’ve got a good relationship with mum, who will describe sort of inappropriate sexual behaviours at home. Well then you can tailor the lessons to make sure you are covering, you know, who is acceptable to be naked around, and when, and where and that sort of thing.” (S: Roy, 72-74)

“It’s adapted each year” (S: Carrie, 87)

“the last one I delivered was on a 1:1 with a girl but that was... in year 9 and she was becoming quite promiscuous. She became aware that she was quite attractive to boys and not knowing when not to be flirtatious. Also, we did a lot on social media because she was making friends with boys in different countries” (S: Carrie, 132-135)

The autism team felt that as staff are becoming more knowledgeable in Autism they will be better able to take on this role:

“If schools have got a better understanding of autism in the first place, they can adapt those materials that they need to be able to deliver it without us having to.” (AOS: Andrew, 259-261)

Staff was also felt that because they work closely with the pupils on a daily basis, they have developed good relationships with the young people and are well positioned to deliver this curriculum as sometimes it could be more comfortable discussing these topics with someone who is not a parent.

“She’s got a very good relationship with them and they feel comfortable with her. She’s also comfortable delivering it.” (S: Carrie, 110-111)
“I feel fairly confident but I think that’s more down to the fact that I’ve supported these boys for quite some time and we know each other quite well. So I know their reactions and they feel comfortable enough to talk to me about it.” (S:alice,90-92)

**AOS’ role**

Amongst the AOS team there was a feeling that their main role in contributing towards delivery of the RSE curriculum was in supporting both parents and schools and that they were very much involved in doing this already in both a proactive but also reactive way.

First and foremost, they see their role as educating school staff and parents, on ASD in general, but also with regards to the RSE curriculum, and this could be through discussions with either staff or parents, or putting on training events.

“Effectively we are the autism translators” (AOS: Andrew,177)

“We are in a position where, where we’re, we’re helping to take information and put that across to staff to empower them to be able to deliver this, the message that they’re wanting to deliver but in an autism friendly way.” (AOS:Andrew,177-180)

“Some people panic, both schools and parents because of the nature of it. So we just want to ground that with, using what we know.” (AOS: Ruth,206-208)

“And then we did uhm... deliver a sort of uhm... a training presentation to parents and schools last year on uh... uhm.. sort of adolescence and looking at adolescence and where that fits in with autism. And ... and then looking at some of the strategies with case studies of how they were used and the outcomes.” (AOS: Lisa,234-237)

“working alongside staff delivering that, we would be there to offer pointers for that more specific, bespoke teaching” (AOS: Bob,188-189)

“we would discuss with, you know, staff actually delivering the general programme which is a lot of what we do.” (AOS: 198-199)
One member of the team described their role as offering direct support to schools for individuals as and when needed, a more reactive response.

“\(I\) think \(w\)e already have a role because \(w\)e respond to the needs that arise and \(w\)e know that particularly in secondary settings, quite often issues do arise around a young person’s understanding, with autism, understanding of relationships. The boyfriend, girlfriend concept and what that means; issues where someone may over focus on an individual. There’s a whole range of issues that might come up, so I think in our role, \(w\)e would definitely see that \(w\)e would support schools in responding to that.” (AOS: Jill,164-169)

This support however, may not involve working directly with a pupil, but rather with the staff who work with the pupil.

“the question about whether we then directly contribute to the sex education, uhm… relationship and sex education in a school, I think, you know…we… I think… we would certainly, where we know a young person has got, or is likely to have those kinds of issues, offer to sort of discuss with the school or with the key person how they might sort of look at embedding certain things within the curriculum but without it being our responsibility to perhaps deliver that because that’s too specific.”(AOS: Jill,169-175)

In addition, The AOS team felt they had a role in sharing with schools or directing school staff and parents to appropriate resources to be used as they regularly access research and evidenced-based strategies that they can share.

“As a team… we…we’ve got some resources or strategies that we would recommend for your young people with autism, those are the same strategies around this. So, is a social story appropriate? Is it about a 1 to 5 scale in terms of physical behaviour?” (AOS: Ruth,201-204)

“we’ll also probably be more concentrating on accessing research, resources and information that shows best practices
and being able to invest ways of doing that whether that’s collectively in putting together a workshop for those people delivering it…” (AOS: Andrew,180-183)

“I think naturally schools are going to be wanting to look for more strategies and more ideas. Schools will often want to come to the... to get the quick fix – Have you got a programme? Have you got something we could just take off the shelf and use? It might be that we need to able to look at that and being able to create something as the twilight sessions out there.” (AOS: Andrew,251-255)

The AOS team also provides a weekly support group to parents of children and young people with ASD, offering general support and teaching but this could also include more specific work on RSE as appropriate.

**Educational Psychologists’ (EP) role**

There was much EPs felt they had to offer within the area of delivering RSE for young people with ASD. The role of the EP was seen to be grounded within the inclusion agenda and the fact that this curriculum needed to be taught to this cohort of pupils as much as any other cohort.

“Yeah I think it is about promoting, there’s an agenda in promoting inclusion, and so all children and young people have the right to be taught about relationships and sex education.” (EP: Lexi,171-173)

EPs felt that they could play a part in raising awareness of this among mainstream teaching staff, broadening their understanding and preparing them for this remit.

“So I would say there’s a role in terms of working with mainstream teaching staff” (EP: Ben,149)
“there’s sometimes a view by some staff that, that umh... they don’t necessarily, they might umh... they might have an expectation that children will already know this and they might make an assumption that children will already know how relationships work, that they might naturally pick those understandings up and it, may be our role to try to work with teachers to broaden their understanding” (EP: Ben,152-157)

“So I think it’s that work in terms of broadening what the teacher’s remit is our role in...” (EP: Ben,161-162)

“I think it’s about empowering staff as well and also empowering staff not to feel embarrassed about it because actually I imagine there will be teachers who will be ‘oh I don’t want to teach that’. Or they don’t feel upskilled enough themselves or have the knowledge themselves....” (EP: Tess,447-450)

Added to this, EPs felt they could help support school staff as well as parents with adapting the curriculum and tailoring it to meet specific needs of young people with ASD.

“There are some adaptations that need to be made to the curriculum or how it’s delivered in order for them to have...to be included in part alongside their peers or do they need something more tailored and bespoke and I think, you know, we could have a role in supporting staff at schools and...and also parents in thinking about how those things are taught to their children.” (EP: Lexi,173-178)

“if that child is able to be included in whole class teaching approach, then that’s fine to do so, but if, if that’s not the case, then looking at alternative ways. We, I think we have a remit there.” (EP: Ben,164-166)

Interestingly, EPs felt they had a role to play in facilitating discussions between home and school in understanding the need for RSE to be taught and how this could be achieved.

“I wondered about kind of facilitating and I guess yeah....process facilitating in terms of ...between parents and schools and trying to... sort of engage them...and their understanding of that ...”(EP:Tess,187-189)

It was felt that EPs could bring something ‘special’ to bear upon existing knowledge and provide a distinct view.
“Our awareness and our understanding of maybe specific vulnerabilities that population might have around sex and relationships and using our understanding of what that might look like for an ASD population and then thinking carefully around how we might communicate how to facilitate this in a positive way but also to be aware of...uhm...any kind of vulnerabilities that may come along with...yeah...having special educational, having additional needs” (EP: Becca,206-211)

Adding to the distinct EP contribution was the feeling that EPs could address the topic of RSE in their reports within the outcomes section and be explicit in their recommendations, which will guide staff and parents in making them aware of their child’s need for this input at an early age.

“I think one way of addressing that someway is addressing it early with outcomes. So we, I think our role there is about, with our reports and through consultations because if we don’t, if we wait till post 16, I think that’s too late, to some extent.” (EP: Ben,402-405)

“Yeah, wanting the long term outcomes, and the life skills and the awareness and how to be, stay safe. But also, you know, in terms of their presentation now, describing them as presenting with difficulty in the boundaries of relationships, you know...going to wrap hug strangers and this kind of thing so you know they’re saying this is what they want...they want them to be able to have an independent life and you know integrate but actually they’re highlighting all these things in terms of relationships, in terms of...being vulnerable but you know their wish is that they are safe and highlighting things that are going on now....” (EP: Tess,422-429)

“I think perhaps we need to make those links for all staff and parents...in terms of well actually, we want them to get to, a kind of, hopefully an independent adult and what that looks like and bridging that gap I suppose and being perhaps maybe explicit in our recommendations or our discussions with staff about things ....they can be very vulnerable, they can potentially be very vulnerable in like a few years’ time if we don’t do something now to address this aspect ....” (EP: Lexi,246-252)

“I wonder whether part of our role is about making those links explicit
Like the AOS group, EPs also felt they could offer something in the way of training:

“ensuring we have a role in that in actually being able to provide a training package or being able to provide something that gets them to feel empowered that maybe they CAN teach it and it’s not something they need to feel embarrassed about or worried about” (EP: Tess, 456-459)

Lastly EPs felt that it may be beneficial to have at least one EP specially trained and skilled in ASD and communication needs to provide specialist knowledge and support to other EPs, as well as school staff and parents. This was seen to be a positive addition to the remit of an EP within a local authority.

“A service and local authority can be enhanced with an EP having a kind of special, specialization effectively, if looking at.. just within the area of autism.” (EP: Ray, 193-194)

“I think that generally though, it’d be, it’s great for a service to have an educational psychologist with a kind of focus on social relationships and how that ties in with social, emotional, mental health needs, or communication needs and so on. I think that could really be quite positive, particularly for our increasing kind of Post 16 kind of uhm... work.” (EP: Ray, 194-198)

5.2.2 Findings for research question 2

Research question 2 was as follows: What barriers might exist to the delivery of RSE for young people with ASD in mainstream settings within this local authority? While findings for this research question produced some interesting data, the researcher was pleasantly surprised that generally speaking, the barriers were being overcome wherever and whenever possible.
A thematic map is shown below:

**Figure 10: Thematic Map for Research Question 2**

Staff all identified resources as a barrier to delivery of this curriculum and this included financial, human and time resources. In terms of financial resources, one SENDCo explained how difficult it was to have staff suitably trained and able to deliver this curriculum particularly with high staff turnover and within the current economic climate. There was also mention of the cost of recommended programmes though this is not a massive hurdle.

“In an ideal world I’d like to think that all of the children with lower ability and special needs were taught in a slightly different manner. Uhm... unfortunately it’s not going to happen because of resources” (S: Carrie,183-185)

“I mean for us it’s always only ever going to come down to cost unfortunately.” (S: Carrie,192-3)

When thinking of human resources, the situation is similar in terms of schools’ ability to employ enough staff to work with pupils in small group or 1:1 situations sometimes required for delivering this curriculum. As a result, schools are having just one member of staff (female) delivering sensitive topics to a group of boys and one cannot help but wonder whether there are safeguarding issues to be considered here.
“the reason we’ve got a female delivering it is because she is the key worker to a few of them in there” (S: Carrie,109)

Time resources was a huge concern for one school where timetabling was cited as a huge barrier to continuing RSE for young people with ASD particularly since the school had merged with another to become an academy.

“At the moment, we don’t and I’ve not figured out how we’re going to do it. Uhm... since the schools merged it’s trickier for a number of complicated reasons to uh... withdraw students from mainstream lessons. There isn’t that personal development lesson at the same time every week where you can kind of conveniently go out for the next rotation of personal development – ‘I’m going to take so and so and so out’ “ (S: Roy,123-127)

Additionally, staff was also finding it difficult as they had more whole class teaching responsibility as a result of the academisation and therefore was unable to fit in extra small group work in this area.

“I don’t have as much non-teaching time on my timetable. I haven’t figured out how to do it yet. I’m hoping to later in the year.” (S:Roy,127-8)

Another barrier identified by staff was the school as a system. One SENDCo described how difficult it had become for him to deliver this curriculum as he did in the past because of his school merging with another to become an academy. Historically he was able to offer a bespoke programme of RSE to pupils with ASD but in the last couple years since the schools merged this has become quite a challenge due to the systems and structures now in place and with his own role being changed somewhat, it has become increasingly difficult to address.

“Like I said, we’ve let things fall by the wayside a bit since the schools merged because there are so many challenges around that. I’d like to deliver the curriculum again” (S:Roy,288-290)
Finally, and to a much lesser extent, pupils’ religious beliefs could pose a barrier.

Occasionally staff came across instances where a pupil’s religious background posed a problem for delivery of this curriculum.

“The only times it’s been really tricky for me is... there uhm... we had 2 brothers who were from a very religious family and uhm.... They were the kind of boys who wouldn’t have wanted to take part and so they were like... ‘this line drawing that you have given me is filth, it’s pornography, our priest would never allow us to look at something like this’. That was tricky to handle.” (S: Roy, 207-211)

But there was also a sense that these pupils just may not have wanted to engage with the subject matter at all regardless of religious beliefs.

“I think they used their religious beliefs almost as an excuse not to...” (S: Roy, 208-209)

“The younger brother I think in the end, we abandoned because he just would not... he would sit in the corner and sulk.” (S: Roy, 218-220)

Lack of willingness to engage with the topic could be an additional barrier within this cohort of pupils and one that will need to be dealt with on an individual basis. While not reported to be a prevalent problem, this, as well as religious beliefs, are still barriers that schools will need to address in a sensitive manner working co-operatively and collaboratively with parents, respecting their views as well as that of the young person.

CHAPTER 6: DISCUSSION

Relationship and sex education is undergoing a ‘shake up’ at the moment which began with the Department for Education’s (2017) announcement that changes to the existing
curriculum were due to come into effect as early as September 2019. A recent BBC News report aired on February 25th 2019, announced that changes to the curriculum will come into force next year (2020) and were being made as a result of added pressures of social media and internet use. The Education Secretary, Damian Hinds, reported that schools needed to do more to support children’s (and young people’s) mental health and well-being acknowledging that positive relationships are linked to good mental health. The report highlighted that the new curriculum would be compulsory for primary and secondary schools and that this was the first update to the curriculum since the year 2000. The report went on to air an interview with Assistant Professor Wendy MacDowell, London School of Hygiene and Tropical Medicine, who claimed that change was needed as the ‘landscape had changed’. Professor MacDowell also highlighted the importance of keeping parents well informed and sharing the responsibility of RSE between parents and schools.

It was against the backdrop of this existing climate and the imminent arrival of this new curriculum that the current research was conceptualised. The present study sought to explore the current situation for young people diagnosed with ASD attending mainstream schools within one local authority in the East Midlands area of England. Views were obtained from various interest groups who work with these young people and included school staff tasked with delivering the new curriculum, the Autism Outreach Team and Educational Psychologists. Parents were included as previous research had indicated that they were best placed and solely responsible for delivering RSE to their Children (Holmes et al. 2016). The researcher also included young people diagnosed with ASD as it was important to obtain pupil voice.
A mixed methods approach was employed with quantitative data gathered through a pupil questionnaire and qualitative data obtained via focus group discussions held for each interest group though staff views were obtained individually because of time constraints. A case study design was used as advocated by Yin (2018). Descriptive statistics was used for the quantitative data and thematic analysis (Braun and Clarke, 2006) was the analytical procedure employed to analyse the qualitative data in order to answer the research questions:

RQ1: How do the thoughts and views of different interest groups within one Local Authority of the Midlands in the UK inform the delivery/non-delivery of the current RSE curriculum to young people diagnosed with ASD attending mainstream settings?

- Research Sub-questions (RSQ):
  - RSQ1.1: ‘How do the views of staff within the local authority affect delivery/non-delivery of the RSE curriculum to young people with a diagnosis of ASD in a mainstream setting?’
  
  - RSQ1.2: ‘How do the views of parents within the local authority affect delivery/non-delivery of the RSE curriculum to their young people with a diagnosis of ASD in a mainstream setting?’
  
  - RSQ1.3: ‘How do the views of young people with ASD in mainstream settings within the local authority affect the delivery/non-delivery of the RSE curriculum?’
RQ1.4: ‘How do the views of the educational psychologists within the local authority impact their role with regards to delivering the curriculum of RSE to young people with a diagnosis of ASD?’

RQ1.5: ‘How do the views of the Autism Outreach Team within the local authority impact their role with regards to delivering the curriculum of RSE to pupils with a diagnosis of ASD in a mainstream setting?’

RQ2: ‘What barriers might exist to the delivery of RSE for young people with ASD in mainstream settings within this local authority?’

The chapter will begin by first identifying the limitations and challenges of the study which will set the context for any conclusions made from the findings of the study. It will then set about to answer the research questions with reference to existing literature and psychological theory. Finally, it will discuss implications for the role of the Educational Psychologist within this particular and often overlooked curriculum area and suggestions for future research.

6.1 Limitations of the research

Firstly, as with previous studies in this field of relationship and sex, there was a relatively small sample size. As the study was a single case study, it was limited to one local authority
and thus restricted to the thoughts and views of this authority alone via five focus groups representing each of the five interest groups, but this made the study manageable and allowed for rigour. The sample size was additionally restricted by the qualitative nature in which data was gathered. A small sample size would mean that extrapolation to the general public would have to be made with caution. Additionally, use of thematic analysis also meant that derived themes would have been based on the researcher’s own interpretation even though every effort was made to make this process as transparent as possible.

There was also the issue of staff participants being interviewed independently rather than in focus groups due to the pressures of getting staff together given their teaching responsibilities and within the timeframe given for collecting data for the research. This meant that responses may have been different to that obtained had they been in a focus group with group dynamics at play such as snowballing (Hess 1968) (reactions to topics leading to reactions from others in the group) and spontaneity (Hess 1968) which could have led to more valuable information being gained. But at the same time, interviewing staff independently could have given them more scope to talk freely and more time to give their views (on average 15-20 minutes per staff participant) than if they were in a focus group for approximately 30 minutes in total.

A further limitation may have come from the mere fact that both pupil and staff participants were recruited from schools that were already implementing a programme of RSE for pupils with ASD. The data gathered from staff therefore would have been already positive as they had already appreciated the need for this curriculum to be delivered. For the pupils they would have had a mostly positive experience compared to if they were attending a school
that did not see a need for this teaching. In addition, the pupil participants were attending a mainstream school but they were also part of the ASD resource unit attached to the school, so not solely mainstream. However, contributions both these groups would still prove useful in identifying shortcomings and areas for improvement.

Furthermore, as with previous studies, the participants were all volunteers and Strassberg and Lowe (1995) report that volunteers for studies on the topic of sexuality tend to be more comfortable with the topic compared to the general public. The parent group in particular may have had a much different approach to the topic compared to other parents so this will have further implications for generalisations. However, as volunteers, it meant that their views were given of their own free will without coercion of the researcher or anyone else for that matter. Being comfortable with the topic also meant they spoke openly and freely which was appreciated by the researcher.

Finally, like in previous studies such as Holmes et al. (2016), the gender of participants may have been a limitation. Among pupils, there was only one female participant and while every effort was made to take her views into consideration, it is difficult to use this one female voice as representative of young women with ASD everywhere. However, this male: female ratio reflects the gender imbalance that exists within the ASD population. Among the parent group it was the same dynamic of previous studies, that is, a high proportion of female parent participants (80%) of predominantly male children.

6.2 Challenges
Many challenges presented within this study. A major challenge was in finding participants for the pupil group. The researcher had initially intended to seek participant young people attending after school clubs, hoping to gain participants from a mix of schools to get a better idea of what was happening across the county. This proved rather difficult as many of these clubs no longer existed due to funding cuts. A decision then had to be made to seek participants through local schools. This presented its own problems, forcing the researcher to make adjustments to the procedure including the use of an initial questionnaire. Most notable however, was having to deal with the school as a gatekeeper and meeting their requirements, including undertaking safeguarding training before being allowed access to the pupils. This threatened the time schedule as the training was delayed. As a result, only participants from one school were used limiting the application of the research not only to the profession but also to the local authority. An antidote to this however, was the use of staff participants from different schools and parents of children and young people attending schools from across the local authority.

A further challenge was the time set aside for interviews. Time was an important factor for all participants. For the pupils, one lesson had been set aside and once the bell went for break time, pupils were eager to get to break and the researcher had to bring the session to an end. For the parents, thirty minutes was afforded before the start of their regular weekly meeting and it was felt that this focus group had to be brought to an abrupt end when the meeting was ready to be commenced. A similar situation ensued for the AOS and EP group with time being slotted in when staff was in the office for their team meetings. The situation was similar for staff with whom the researcher could not get together all at the same time and had to eventually interview individually. The researcher felt she was always ‘stealing’
some time but was grateful for the opportunity to progress her research.

An unexpected challenge came in the form of understanding the programme and its use. It did not help that there were different versions and upgrades with different platforms. Having now used Nvivo, the researcher believes she could have done just as well doing the analysis manually. This is not to say that Nvivo is faulty or unhelpful but the researcher was unable to fully capitalise on the use of Nvivo and would have benefitted from some tuition in using the programme as she believes there is much to gain from it. Nvivo, the researcher believes, once understood fully, can give qualitative research a quantitative element and can add to the rigour of analysis.

6.3 Research questions answered

The study aimed to answer the research question:

**RQ1: How do the thoughts and views of different interest groups within one Local Authority of the Midlands in the UK inform the delivery/non-delivery of the current RSE curriculum to young people diagnosed with ASD attending mainstream settings?**

as well as:

**What barriers might exist to the delivery of RSE for young people with ASD in mainstream settings within this local authority?**

As a case study design was used, an initial theory was developed as follows:

*The case study will show that the thoughts and views of the different adult interest groups within the local authority are preventing the successful implementation of RSE to young*
**RSE FOR YOUNG PEOPLE WITH ASD**

*persons with ASD in mainstream schools. It will show how to address these barriers to bring about change.*

Contrary to the theory put forward however, findings indicated that not only were the thoughts and views of the different interest groups in the LA very broad and positive, but that RSE was being implemented with some success in quite a few schools and that while some barriers were in place, relevant parties were aware of these and were working towards addressing these, though this was not always immediately possible.

The general consensus across all interest groups was that it was important to teach RSE to pupils with ASD. Parents all wanted happy and positive futures for their children and young people with ASD and understood the importance of an appropriate RSE curriculum delivered at school to support them and their child in achieving this outcome. Across all groups there was a broad understanding of RSE and what it entails. This came as a bit of a surprise to the researcher as previous studies such as that conducted by Nichols and Blakeley-Smith (2010) had found that parents in particular, often equated sex/sexuality with sexual intercourse and that there was a very narrow view of the topic. This was definitely not the case in the current research and across all groups, participants thought that RSE needed to be grounded with a good understanding of the ‘relationship’ element with the ‘sex’ element following later on. In most cases, the ‘sex’ element seemed to have been a job for Science and covered within that subject area. There may be something to be said about the use of the term ‘Relationship and Sex Education’ (as opposed to Sex education) which immediately places the focus on relationships and is the term to be used in the new curriculum for this very reason. However, it was reassuring to see that general
understanding of the topic had progressed (from earlier studies) and that it is now given a lot more depth than before, encompassing the need for positive relationship building above everything else.

All groups reiterated the view that young people with ASD had specific needs and acknowledged that special consideration had to be given to this cohort for a variety of reasons. The views of the various interest groups will best be discussed within the subthemes “Why teach RSE”, “What to teach”, “How to teach” and “When to teach” as well as “Everyone’s responsibility”.

6.3.1 Why teach RSE

Across all groups various reasons were given for the teaching of RSE, but these were all linked to the fact that the neurological differences experienced by those diagnosed with ASD will mean that they require information to be made explicit and to be presented in a slightly different format to that for typically developing young people. Within the EP group it was felt that it was important to make this curriculum available to young people with ASD just as any other curriculum simply because of the inclusion agenda. EPs felt that excluding this cohort from this teaching would just be fundamentally wrong and not in keeping with the rights of the child set out in the UN Convention (1989), Article 23 (stated earlier).

The vulnerability of young people within this cohort was another reason given by various groups including staff, EPs and even pupils cited their own vulnerability as a reason for teaching/learning more about RSE. Previous studies had already highlighted the risks to those with ASD and the associated social impairments. Brown-Lavoie et al (2014) had
claimed that those with ASD were often two to three times more susceptible to sexual exploitation due to their lack of social judgement and inability to understand social expectations. As a result of this it was felt that certain things need to be made overly explicit for these young people such as for example: the difference between a ‘safe’ and ‘unsafe’ person. The current study also identified the influence of social media as a threat to this cohort’s safety when it comes to RSE which is in keeping with the ideas put forward by the Department for Education (2017).

6.3.2 What to teach

When thinking of ‘what to teach’, there was again consensus across the groups on specific topics to be included and given more emphasis based on current trends in technology and culture. Among the adult groups, safety was a huge concern given the difficulties with communication for this cohort. Of specific interest was internet safety particularly as so many young people in general, but also those with ASD spend much time online watching videos or gaming and possibly meeting strangers online. So protocols here really do need to be made explicit.

Also of importance was gender identity and here parents really made it clear that they want their children to feel comfortable in their own skin and to be able to explore their gender as they see fit. The professional groups also felt this was an important topic to cover in the current climate as did the pupils who felt that this was not given much emphasis in the past.

Gilmour et al. (2012) reports a higher number of ASD individuals reporting to be gay or bi-
sexual than in the general public so it would be important to address this aspect of sexuality in a RSE curriculum for this cohort.

The topic of consent was a significant one for parents in particular who felt this could be taught at an early age and developed as the child grows. For EPs, consent had much to do with language and communication which is an area of high need for pupils with an ASD diagnosis so this was seen as a really important concept to get across to the young person so there are no shady areas. Misunderstanding consent could have long lasting as well as legal repercussions.

The practical aspects of RSE was identified as another area of focus by the pupil group. Like previous research such as that of Hannah and Stagg (2016), pupils found that while they are taught the basics of RSE they are still left unsure of how to go about navigating relationships. It must be said that this would be difficult to teach even to young people without an ASD diagnosis, but it was here that these ASD youths felt they needed some support.

6.3.3 How to teach
It was felt that a consideration of individual needs would encompass all the thoughts and views across the various groups with regards to how RSE should be taught. All reiterated that no ‘one size fits all’ approach would work and that while the curriculum had to be tailored for this cohort, further adjustments were needed within the cohort to ensure that individual needs were being met. It has often been said that ‘meeting one person with ASD is just that, you’ve met one person with ASD’. Similarly, a RSE curriculum will need to be
tailored to individual needs for it to be effective for the young person with ASD. One such curriculum resource was that of Fiona Speirs (A PHSE Programme for Learners with Autistic Spectrum Disorders) as recommended to schools by the Autism Outreach team within this local authority, with a caveat that it is to be used as a guide. Staff who were using this programme spoke highly of it. Previous research (Nichols and Blakeley-Smith, 2009) had identified a lack of appropriate resource materials for use in teaching young people about RSE.

Findings suggest that the issue of gender, in terms of teaching to single gender groups and the gender of the teacher delivering the curriculum is not of huge importance to male pupils. The lone female participant however, shared a preference for same sex teacher and groupings. Additionally, pupils recommend more emphasis on the practical skills required in developing relationships and more guidance on the transfer of these skills to real life scenarios.

6.3.4 When to teach

The findings suggest that teaching should begin at an early age with a focus on relationships and added to as the child grew older. A spiral approach, teaching little at a time over consecutive years, was thought best as opposed to doing everything at the start of adolescence never to be returned to again, the preferred option of one pupil.

6.3.5 Everyone’s responsibility

Across all groups it was felt that everyone had a responsibility, a role to play in delivering this curriculum. Parents felt solely responsible and it was encouraging to see that since previous research, parents’ thinking and confidence had improved significantly. They were
however, happy to share the role with school, willing to receive some help, and for someone to ‘start things off’, as long as they were well informed of what was being taught and when.

The AOS team saw their role as one of teaching/training to upskill parents and school staff so they are better placed to deliver this curriculum. School staff are in the enviable position of actually delivering this curriculum to pupils and saw their role as being very important as they have a different kind of relationship with pupils compared to what pupils have with parents and felt pupils would respond better to them as authority figures and heed their teaching. Additionally, it could be more comfortable discussing this subject matter with someone other than a parent. Staff saw their role as key allowing pupils opportunity for frank, open, honest discussion within smaller groupings.

**The role of the EP**

Historically, there has not been much input within the field of educational psychology on this particular subject of RSE for pupils with ASD. No studies were found within educational psychology literature. However, findings suggest that EPs do feel that there is a role for them within this area and there is much they can offer by way of changing attitudes/thinking about RSE and ASD and so help to foster positive mental health and well-being outcomes for young people with ASD.

To start with, EPs have a good understanding of child development and what is considered typical and atypical development. Within the local authority, EPs are involved in the Autism Pathway and the diagnosis of Autism Spectrum Disorder and so are knowledgeable in the
needs of children and young people with an ASD diagnosis. EPs are well versed in the social communication and interaction needs of young people with ASD and the ways in which this can impact their development of friendships and relationships. As such, findings indicate that EPs feel that they could play a role in broadening understanding of mainstream staff, empowering them to feel ready to take on the challenge of the new compulsory RSE curriculum when it comes into effect. It is known that some staff could feel embarrassed (as was the case of the researcher’s own personal experience), but EPs felt that with better understanding of the needs of the young people, staff could put their shame aside and reconfigure their thinking, putting the needs of the young people first and foremost. This, they felt, could be addressed through a relevant training package.

Findings also suggest that EPs may have a role in being facilitators of conversations between home and school regarding RSE, maybe starting things in motion where there is a need and guiding discussions to encourage collaboration between parents and schools to ensure joint working on this much needed area of learning. This could be well placed within the ‘Preparing for Adulthood’ framework and could be addressed in the outcomes section of EP reports. In this way both parents and staff would be signposted to the need to address this aspect of the young person’s development and learning.

A key finding for the role of the EP was the development of specialisms. EPs felt that it would be beneficial to local authorities to have an EP specially trained in the field of ASD to provide specialist knowledge not only to other EPs but also to school staff and parents. It was felt that this role was covered by the Autism Outreach team in this local authority but for wider application, this might be a role for an EP to consider particularly where there may be no specialist Autism support.
Findings to Research Question 2 indicate that there were few barriers being faced by staff but that these barriers in some instances had significant impact on delivery of the RSE curriculum with some pupils having to settle with regular mainstream classes and no additional bespoke input. It was found that the academisation of schools could be putting pressure on staff and timetabling making it really difficult, even not at all possible, to deliver targeted RSE to pupils with ASD needs. This will be an area for consideration as more and more schools become academies and the compulsory curriculum is introduced.

6.4 Theoretical perspectives revisited

Bronfenbrenner’s Ecological systems theory

To put the findings into a theoretical context, let us again look at Bronfenbrenner’s ecological systems theory (1994), explained in Chapter 3. For any child, and particularly those with ASD the ecological system would provide insight into their development. The various interest groups in this study would be seen to form part of the young person’s micro system with the influence of social media and the local authority operating within the exosystem. At a macro system level will be the new curriculum due to come into force next year. A diagrammatic representation is shown below:

Figure 11: An Ecological Model (developed by the researcher) as it applies to the young person with ASD in this study (based on Bronfenbrenner’s model as adapted by Santrock and Yussen, 1992)
These various influences are all impacting on the continued development of the relationship and sex education of the person diagnosed with ASD and encapsulates one of the overriding themes of the research – Collective responsibility. It shows clearly how all the various systems within the young ASD individual’s environment – parents, school, EPs, AOS team, local authority, even social media with a responsibility to its service users - has some part to play, some impact on their developing relationship and sex education.

Theory of Reasoned Action

This theory put forward by Ajzen and Fishbein (1980) attempts to predict behavioural intention by considering factors that may prevent an action from being carried out. At the onset of the current study it was thought that the attitudes of various interest groups might be impeding delivery of RSE to ASD pupils. This however was not the case. The theory still applies though as the findings suggest that the attitudes of those working with young people were actually quite positive with regards to RSE. All participants had a good
understanding of RSE and how important it was to be delivered to young people in general but particularly so for those with ASD. This captures the other overriding theme of ‘Positive Perceptions’ and the general understanding of RSE held by the different interest groups. This impacts positively on attitudes and filters ultimately to all aspects of delivery of the curriculum – what to teach, when to teach, how to teach and why teach.

Attitudes were impacting positively on behaviour as the study discovered. RSE was taking place for ASD pupils and where this was not happening, there was intent to do so. Parents were taking responsibility for having these discussions with their young people and conversations were being held between the professionals (EPs and AOS) and schools and parents.

One concerning attitude however, was among EPs. The researcher found that those who volunteered for the study were younger in age or earlier in their profession (some still training). The more experienced EPs did not choose to participate with one even commenting that she did not think she had much to offer in this area. This left the researcher wondering if there was still some ‘taboo’ around the subject of sex that made the older, more experienced EPs somewhat uncomfortable. Hopefully this research could address some of these lingering attitudes of times past and highlight a niche role for the EP in helping to address this all too important curriculum area.

6.5 Dissemination plan
At the start of this research, the proposal was shared with the Director of Children’s Services and the Principal Educational Psychologist at the local authority where the research was conducted. It is planned that the researcher will get an audience with these individuals again to share the results via a face to face presentation in the hope that these policy makers could be directed accordingly.

The results would also be shared through face to face presentation and discussion with the EP team (including the EP participants) during one of their team meetings.

For other participants, an executive summary will be compiled and this will be shared via email with opportunity for further discussion provided if needed.

6.6 Conclusion

To summarise, the findings of the current study were able to shed some light on the situation for ASD pupils in relation to the teaching of RSE within one local authority. The research found that across interest groups, there was a positive perception about this topic with all feeling that it was relevant and needed to be delivered in a bespoke manner to an ASD cohort, tailored to individual needs. Tailoring the curriculum to meet individual needs was recommended in previous research such as that of Hannah and Stagg (2016). All felt they had a role to play in making delivery possible.

What this research added to existing research were the views of staff and their thoughts about delivering this curriculum. Findings here were that, according to participants in the
study, where the curriculum was already being delivered, staff felt equipped and expert enough to do this and saw value in their contribution to the social development of young people with ASD needs. Further research could focus on a wider catchment of pupils and staff so a better idea of the local and national situation could be obtained. Additional research could also include what the situation is like for pupils and staff where perhaps there is no provision made for this cohort of pupils.

Furthermore, the research also added input from educational psychology which had been mostly silent on this issue thus far. Within the profession there has been acknowledgement of this topic as one requiring some consideration as evidenced by the Association of Educational Psychologists’ (AEP) Educational Psychology Autism Special Interest Group (EPASIG). This topic was the subject of their 2017 conference and the researcher made a presentation the current research (proposal stage at that time) at the 2018 conference.

It was hoped that the research would bring about positive change in the way RSE was being delivered within the local authority and to thinking about RSE in light of the new curriculum soon to be in force. It was hoped that incorporating the views of the young people on the receiving end would make RSE more relevant and meaningful for them. It must be said that the situation within the local authority appears much better than the researcher anticipated and there seems to be a good understanding of RSE and ASD which in turn will mean that proper provision will be made for this group. Though RSE appears to be well delivered, there was one parent spoke of her husband’s annoyance with a school who began RSE instruction to their son without first seeking parental consent which suggests that there is room for improvements to be made. Thus far, the researcher has been informed of change already taking place as members of the AOS team have set targets around RSE following the focus
group discussion as certain factors were highlighted and brought to the fore.

The new hope is that the research would raise the profile of RSE for pupils with ASD and endorse the work already being done and encourage those both within the local authority and further afield who may not yet be addressing the RSE needs of ASD pupils to gain some insight into this issue and address this gap which definitely exists in some mainstream schools. It is imperative to address this issue so that these young people have an opportunity, just like anyone else, to live a full and decent life with positive mental health outcomes. Working within a critical realist position, the researcher hopes to support the ‘pursuit of social justice and the furtherance of human rights’ (Mertens, 2012, p.2).


RSE FOR YOUNG PEOPLE WITH ASD


Tufford, L. and Newman, P. (2010). Bracketing in Qualitative Research. *Qualitative Social Work*. Vol 0(0), 1-17


[Accessed on 27th October, 2017]


[Accessed on 2nd January 2018]

## APPENDICES

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Appendix 1

Ethics Approval Letter from University of Sheffield
Dear Roxanne

**PROJECT TITLE:** Relationship and Sex Education for young people with Autistic Spectrum Disorder  
**APPLICATION:** Reference Number 018393

On behalf of the University ethics reviewers who reviewed your project, I am pleased to inform you that on 23/05/2018 the above-named project was **approved** on ethics grounds, on the basis that you will adhere to the following documentation that you submitted for ethics review:

- University research ethics application form 018393 (dated 22/05/2018).
- Participant information sheet 1044698 version 1 (21/05/2018).
- Participant information sheet 1043096 version 2 (21/05/2018).
- Participant information sheet 1042363 version 1 (09/04/2018).
- Participant consent form 1042345 version 3 (04/05/2018).
- Participant consent form 1042344 version 4 (21/05/2018).
- Participant consent form 1042342 version 3 (04/05/2018).
- Participant consent form 1042341 version 2 (27/04/2018).
- Participant consent form 1042340 version 2 (27/04/2018).

If during the course of the project you need to **deviate significantly from the above-approved documentation**, please inform me since written approval will be required.

Yours sincerely

David Hyatt  
Ethics Administrator  
School of Education
Appendix 2

Pupil Information Letter
Hello,

You are being invited to participate in a research project by me, Roxanne Kaba, a student at the University of Sheffield. Before you decide if you would like to take part, it is important for you to understand more about the research. Please read the following information carefully and decide whether or not you would like to participate.

The aim of the research is to find out how Relationship and Sex Education (RSE) is taught to pupils in the part of England where you live. I am particularly interested in pupils with a diagnosis of Autism in mainstream schools. I would like to find out what it was like for you when you had these lessons at school. I want to know how you feel about the way these lessons were taught - What was done well? What could have been better?

I would also be speaking to parents, teachers and other people who work with children with Autism to see what they think as well.

I understand that you might feel a bit embarrassed to talk about this topic but I want you to know that whatever you share with me would be made anonymous. This means that your name would not be used and no one would be able to connect you with the information. However, if you share something and it makes me worried about your safety, then I will have to pass that information on to someone who could help keep you safe.

I would first be asking you to complete a short questionnaire giving your opinion about your experience of RSE. This will be anonymous. Once you have completed the questionnaire you can decide if you want to discuss your opinions in more detail within a small group of pupils, about 2 to 4 in total, from your school. In

Pupil Information Form
this group I will be recording your voices so I could have the information I need to write up my project. Once I am finished writing, the recordings would be destroyed and no one else would be able to use them or link the information with you in any way.

I will share the results of the research project with you and also with others who work with young people with Autism so they can know how to improve Relationship and Sex Education for all persons with Autism.

Taking part in this project is all your choice and if you decide to take part you will need to sign a 'consent form'. However, you can change your mind at any time and without having to give a reason. It is all up to you.

If you do decide to take part, please add your name below and return the form to your teacher.

I look forward to working with you on my project!

Roxanne 😊

PS
If you have any questions or concerns about the project, you can discuss it with your teacher who can contact me for more information.

Interest in Participating

I would like to take part in this research project called: 'Relationship and Sex Education for young people with Autistic Spectrum Disorders/Aspergers in mainstream settings'

Name:  ..............................................................
Appendix 3

Pupil Questionnaire Consent Form
Pupil Questionnaire Consent Form

Title of Research Project: Relationship and Sex Education for young people with Autism Spectrum Disorder in mainstream settings.

Name of Researcher: Roxanne Njopa-Kaba

Participant Identification Number for this project: Please initial box

1) I understand what the questionnaire is about and I have been able to ask questions about anything I didn't understand.

2) I understand that it is my choice whether or not I complete the questionnaire. I can change my mind at any time without giving any reason. I will not be punished for this. I can also refuse to answer any questions if I feel uncomfortable.

3) I understand that my name will not be linked to anything I write on the questionnaire. I will be 'anonymous'.

4) I agree for what I have said to be used in future research as long as my name is not linked to it.

6) I agree that my information could be passed on to someone else if I need to be kept safe.

7) I agree to be part of a small group of about 2 to 4 pupils to talk about my ideas in some more detail. I can change my mind about this at any time.

_________________________ Date ______________ Signature
Your Name __________________________

_________________________ Date ______________ Signature
Researcher’s Name __________________________

To be signed and dated in presence of the participant

Copies: Participant, Researcher
Appendix 4

Pupil Consent Form
Pupil Consent Form

Title of Research Project: Relationship and Sex Education for young people with Autism Spectrum Disorder in mainstream settings.

Name of Researcher: Roxanne Njopa-Kaba

Participant Identification Number for this project: Please initial box

1. I understand what this project is about and I have been able to ask questions about anything I didn't understand.

2. I understand that it is my choice whether or not I participate in this research and that I can change my mind at any time without giving any reason. I will not be punished for this. I can also refuse to answer any questions if I feel uncomfortable.

(Contact Roxanne Njopa-Kaba on rnjopakaba1@sheffield.ac.uk if you feel you do not want to continue with the research)

3. I understand that my name will not be linked to anything I say during this research. I will be 'anonymous'.

4. I agree for what I have said to be used in future research as long as my name is not linked to it.

I agree to take part in this research project and not share anything that is said in the research group with anyone else.

6. I agree that my information could be passed on to someone else if I need to be kept safe.

________________________ ___________________ ____________________
Your Name Date Signature
(or legal representative)

________________________ ___________________ ____________________
Researcher's Name Date Signature

To be signed and dated in presence of the participant
Copies: Participant, Researcher
Appendix 5

Pupil Questionnaire
Pupil Questionnaire

Please read each statement carefully, then tick the boxes to show if you agree, disagree or if you are not sure.
Relationship and sex education will be called ‘RSE’

<table>
<thead>
<tr>
<th>Statements</th>
<th>Disagree</th>
<th>Not sure</th>
<th>Agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 I know what RSE is all about.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2 My parents have spoken to me about RSE.</td>
<td></td>
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<tr>
<td>3 I have lessons, or have had lessons in the past, about RSE at my school.</td>
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<tr>
<td>4 I enjoyed my lessons about RSE.</td>
<td></td>
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<tr>
<td>5 I would like to know more about RSE.</td>
<td></td>
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<tr>
<td>6 I know who I can go to if I have questions about RSE.</td>
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<tr>
<td>8 I think the following topics should be included in a programme that teaches about RSE.</td>
<td></td>
<td></td>
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<tr>
<td>Making and keeping friends</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Safe sex</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Contraception - Preventing pregnancy</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Consent- agreement to do something</td>
<td></td>
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<tr>
<td>Dating</td>
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<tr>
<td>Any others:</td>
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<tr>
<td>9 What do think would be the best way to teach young people at school with ASD about relationships and sex?</td>
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<tr>
<td>Small groups, not in class with everyone else.</td>
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<tr>
<td>Open discussion</td>
<td></td>
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<tr>
<td>Mixed group - boys and girls</td>
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<tr>
<td>With a teacher of the same gender as the pupils</td>
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<tr>
<td>Any other ideas?</td>
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<tr>
<td>10</td>
<td><strong>What do you think is the right age for learning about RSE at school?</strong></td>
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<td></td>
<td><strong>Why do you think this age is right?</strong></td>
<td></td>
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</table>
Appendix 6

Questionnaire Results
Pupil Questionnaire

Please read each statement carefully, then tick the boxes to show if you agree, disagree or if you are not sure.

Relationship and sex education will be called ‘RSE’

<table>
<thead>
<tr>
<th>Statements</th>
<th>Disagree</th>
<th>Not sure</th>
<th>Agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>I know what RSE is all about.</td>
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<td>III</td>
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<tr>
<td>My parents have spoken to me about RSE.</td>
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<tr>
<td>I have lessons, or have had lessons in the past, about RSE at my school.</td>
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<td>II</td>
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<tr>
<td>I enjoyed my lessons about RSE.</td>
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<td></td>
<td>III</td>
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<tr>
<td>I would like to know more about RSE.</td>
<td></td>
<td></td>
<td>III</td>
</tr>
<tr>
<td>I know who I can go to if I have questions about RSE.</td>
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<td></td>
<td>III</td>
</tr>
<tr>
<td>I think the following topics should be included in a programme that</td>
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<tr>
<td>teaches about RSE.</td>
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<td></td>
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<tr>
<td>Making and keeping friends</td>
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<td>II</td>
<td></td>
</tr>
<tr>
<td>Safe sex</td>
<td></td>
<td>II</td>
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<tr>
<td>Contraception - Preventing pregnancy</td>
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<tr>
<td>Consent - agreement to do something</td>
<td></td>
<td>II</td>
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<tr>
<td>Dating</td>
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<tr>
<td>Any others:</td>
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<tr>
<td>What do you think would be the best way to teach young people at school</td>
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<td>with ASD about relationships and sex?</td>
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<tr>
<td>Small groups, not in class with everyone else.</td>
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<td>II</td>
<td>I</td>
</tr>
<tr>
<td>Open discussion</td>
<td></td>
<td>II</td>
<td>III</td>
</tr>
<tr>
<td>Mixed group - boys and girls</td>
<td></td>
<td>I</td>
<td>II</td>
</tr>
<tr>
<td>With a teacher of the same gender as the pupils</td>
<td></td>
<td>II</td>
<td>I</td>
</tr>
<tr>
<td>Any other ideas?</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
9. What do you think is the right age for learning about RSE at school?

12 / 15 / 15 / Yr 7

Why do you think this age is right?

Mature / more sensible
Appendix 7

Information Letter for parents of ASD Pupils
Your son/daughter is being invited to participate in a doctoral research thesis project conducted by a student of the Doctorate of Educational and Child Psychology programme at the University of Sheffield. The research would take the form of a case study of the local authority where you live. Please take time to read the following information carefully so you are aware of your child’s involvement in this project.

Research indicates that parents are best placed for delivering Relationship and Sex Education (RSE) to their children, particularly those with a Special Educational Need (SEN). However, the research has also revealed that parents aren’t always aware, skilled or have knowledge in this area. Additionally, as more and more pupils diagnosed with an Autism Spectrum Disorder (ASD) attend mainstream provisions, coupled with the onset of the new government legislation in 2019, making the teaching of RSE compulsory in all primary and secondary schools, the delivery of RSE is becoming part of the remit of mainstream school staff.

The aim of the research is to explore the current situation within one local authority (LA) in the East Midlands area of England by means of a case study approach. The researcher wants to explore how RSE is currently being addressed for those young people who are diagnosed with ASD and attending a mainstream setting. The researcher wants to explore the topic from different perspectives and will include the views of parents of young people with an ASD diagnosis, the young people themselves, their teachers, the Autism outreach team who offer support at school and at home and the Educational Psychologists who work with all of these parties. The purpose of the research is to answer the question:

‘How do the thoughts and views of different interest groups within one local authority of the Midlands of the UK inform its provision of RSE for young people with a diagnosis of ASD, attending a mainstream provision?’

Your child has been chosen for selection to participate in the study because he/she falls within one of the interest groups listed above, however, participation is completely voluntary. Your child will be given an information letter to keep and will be asked to sign a consent form. He/she can withdraw from the study at any time and without reason.
Your child’s participation would involve him/her firstly completing an anonymous questionnaire giving their opinion on various aspects of RSE provision. Then, if they wish to discuss these opinions in more detail, they can volunteer to be part of a small focus group discussion that would last no longer than ½ an hour. These discussions will take place at school and would be audio recorded using a digital audio recorder, then transcribed for analysis. During discussions first names only may be used (to assist the researcher in knowing who is speaking on the audio recordings) but pseudo names would be used when transcribing to ensure their anonymity. All data collected would be kept strictly confidential and in a locked cupboard accessed only by the researcher. Following anonymised analysis, all data will be destroyed.

Analysed data and results of the study would be shared with the participants, in the first instance, and with the local authority Director of Children’s Services as well as the Principal Educational Psychologist. It will also be shared with university tutors, other doctoral students and other local authorities. The results may also be published in research journals and made available online via Whiterose theses.

I would like to take this opportunity to thank you for reading this information sheet. If you have any questions or concerns about the project and/or your child’s involvement, please do not hesitate to contact me via email:

Roxanne Njopa-Kaba - rnjopakaba1@sheffield.ac.uk

or my Research Tutor via email:
Dr Lorraine Campbell - l.n.campbell@sheffield.ac.uk

Please complete and return to school:

Parental consent

I agree to my son/daughter taking part in this research project called: ‘Relationship and Sex Education for young people with Autistic Spectrum Disorders/Aspergers in mainstream settings’.

Name: ........................................................................................................

Signature: .................................................................................................

Date: .........................................................................................................

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Appendix 8

Information Letter for Adult Participants
You are being invited to participate in a doctoral research thesis project conducted by a student of the Doctorate of Educational and Child Psychology programme at the University of Sheffield. The research would take the form of a case study of the local authority where you live or work. Before you decide if you would like to participate, it is important for you to understand more about the research. Please take time to read the following information carefully and decide whether or not you would like to participate.

Research indicates that parents are best placed for delivering Relationship and Sex Education (RSE) to their children, particularly those with a Special Educational Need (SEN). However, the research has also revealed that parents aren't always aware, skilled or have knowledge in this area. Additionally, as more and more pupils diagnosed with an Autism Spectrum Disorder (ASD) attend mainstream provisions, coupled with the onset of the new government legislation in 2019, making the teaching of RSE compulsory in all primary and secondary schools, the delivery of RSE is becoming part of the remit of mainstream school staff.

The aim of the research is to explore the current situation within one local authority (LA) in the East Midlands area of England by means of a case study approach. The researcher wants to explore how RSE is currently being addressed for those young people who are diagnosed with ASD and attending a mainstream setting. The researcher wants to explore the topic from different perspectives and will include the views of parents of young people with an ASD diagnosis, the young people themselves, their teachers, the Autism outreach team who offer support at school and at home and the Educational Psychologists who work with all of these parties. The purpose of the research is to answer the question:

‘How do the thoughts and views of different interest groups within one local authority of the Midlands of the UK inform its provision of RSE for young people with a diagnosis of ASD, attending a mainstream provision?’

You have been chosen for selection to participate in the study because you fall within one of the interest groups listed above, however, participation is completely voluntary. It is up to you to decide whether or not to take part. If you do decide to take part, you will be given this information sheet to keep (and be asked to sign a consent form) and you can still withdraw at any time. You do not have to give a reason.
Your participation would involve you being part of a focus group discussion that would last approximately 1 to 1 1/2 hours. These discussions would be audio recorded using a digital audio recorder and transcribed for analysis. During discussions your first name only may be used (to assist the researcher in knowing who is speaking on the audio recordings) but pseudo names would be used when transcribing to ensure your anonymity. All data collected would be kept strictly confidential and in a locked cupboard accessed only by the researcher. Following anonymised analysis, all data will be destroyed.

Analysed data and results of the study would be shared with you, the participants, in the first instance, and with the local authority Director of Children’s Services as well as the Principal Educational Psychologist. It will also be shared with university tutors, other doctoral students and other local authorities. The results may also be published in research journals and made available online via Whiterose theses.

If you do decide to take part, please complete the ‘Interest in Participating’ form and return to the researcher by the date given.

I would like to take this opportunity to thank you for reading this information sheet and considering participation in my research thesis project. If you have any questions or concerns about the project, please do not hesitate to contact me via email: Roxanne Njopa-Kaba - rnjopakaba1@sheffield.ac.uk or my research tutor via email: Dr Lorraine Campbell - l.n.campbell@sheffield.ac.uk

--------------------------------------------------------------------------------------------------------------------------

**Interest in Participating**

I wish to indicate my interest in participating in the research project titled:

*‘Relationship and Sex Education for young people with Autistic Spectrum Disorders in mainstream settings’*

Name: ........................................................................................................................................

Please tick:

Parent [ ] School staff member [ ]

Autism Outreach staff member [ ] Educational Psychologist [ ]
Appendix 9

EP Consent Form
Title of Research Project: Relationship and Sex Education for young people with Autism Spectrum Disorder in mainstream settings.

Name of Researcher: Roxanne Njopa-Kaba

Participant Identification Number for this project: Please initial box

1. I confirm that I have read and understand the information sheet/letter dated May 2018 explaining the above research project and I have had the opportunity to ask questions about the project.

2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason and without there being any negative consequences. In addition, should I not wish to answer any particular question or questions, I am free to decline. (Contact Roxanne Njopa–Kaba on rnjopakaba1@sheffield.ac.uk to exercise this right)

3. I understand that my responses will be kept strictly confidential and I am not to share anything said by others within the focus group. I give permission for members of the research team to have access to my anonymised responses. I understand that my name will not be linked with the research materials, and I will not be identified or identifiable in the report or reports that result from the research.

4. I agree for the anonymised data collected from me to be used in future research.

5. I agree to take part in the above research project.

__________________________ ____________________________ ____________________
Name of Participant Date Signature
(or legal representative)

__________________________ ____________________________
Name of person taking consent Date Signature
(if different from lead researcher)
To be signed and dated in presence of the participant

__________________________ ____________________________
Lead Researcher Date Signature
To be signed and dated in presence of the participant

Copies: Participant Researcher
Appendix 10

Parent Consent Form
Title of Research Project: Relationship and Sex Education for young people with Autism Spectrum Disorder in mainstream settings.

Name of Researcher: Roxanne Njopa-Kaba

Participant Identification Number for this project: Please initial box

1. I confirm that I have read and understand the information sheet/letter dated May 2018 explaining the above research project and I have had the opportunity to ask questions about the project.

2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason and without there being any negative consequences. In addition, should I not wish to answer any particular question or questions, I am free to decline. (Contact Roxanne Njopa-Kaba on rnjopakaba1@sheffield.ac.uk to exercise this right)

3. I understand that my responses will be kept strictly confidential and I am not to share anything said by others within the focus group. I give permission for members of the research team to have access to my anonymised responses. I understand that my name will not be linked with the research materials, and I will not be identified or identifiable in the report or reports that result from the research.

4. I agree for the anonymised data collected from me to be used in future research

5. I agree to take part in the above research project.

<table>
<thead>
<tr>
<th>Name of Participant</th>
<th>Date</th>
<th>Signature</th>
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<td>(or legal representative)</td>
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<table>
<thead>
<tr>
<th>Name of person taking consent</th>
<th>Date</th>
<th>Signature</th>
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<tbody>
<tr>
<td>(if different from lead researcher)</td>
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</table>

To be signed and dated in presence of the participant

<table>
<thead>
<tr>
<th>Lead Researcher</th>
<th>Date</th>
<th>Signature</th>
</tr>
</thead>
</table>

To be signed and dated in presence of the participant

Copies: Participant Researcher
Appendix 11

Staff Consent Form
Staff Consent Form

**Title of Research Project:** Relationship and Sex Education for young people with Autism Spectrum Disorder in mainstream settings.

Name of Researcher: Roxanne Njopa-Kaba

Participant Identification Number for this project: Please initial box

1. I confirm that I have read and understand the information sheet/letter dated **May 2018** explaining the above research project and I have had the opportunity to ask questions about the project.

2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason and without there being any negative consequences. In addition, should I not wish to answer any particular question or questions, I am free to decline. *(Contact Roxanne Njopa–Kaba on rnjopakaba1@sheffield.ac.uk to exercise this right)*

3. I understand that my responses will be kept strictly confidential and I Am not to share anything said by others within the focus group. I give permission for members of the research team to have access to my anonymised responses. I understand that my name will not be linked with the research materials, and I will not be identified or identifiable in the report or reports that result from the research.

4. I agree for the anonymised data collected from me to be used in future research

5. I agree to take part in the above research project.

_______________________ __________________ ___
Name of Participant Date Signature
(or legal representative)

_________________________ ____________________
Name of person taking consent Date Signature
(if different from lead researcher)
*To be signed and dated in presence of the participant*

_________________________ ____________________
Lead Researcher Date Signature
*To be signed and dated in presence of the participant*

Copies: Participant

Researcher
Appendix 12

AOS Consent Form
## Autism Staff Consent Form

**Title of Research Project:** Relationship and Sex Education for young people with Autism Spectrum Disorder in mainstream settings.

Name of Researcher: Roxanne Njopa–Kaba

Participant Identification Number for this project: Please initial box

1. I confirm that I have read and understand the information sheet/letter dated May 2018 explaining the above research project and I have had the opportunity to ask questions about the project.

2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason and without there being any negative consequences. In addition, should I not wish to answer any particular question or questions, I am free to decline. *(Contact Roxanne Njopa–Kaba on rnjopakaba1@sheffield.ac.uk to exercise this right)*

3. I understand that my responses will be kept strictly confidential and I am not to share anything said by others within the focus group. I give permission for members of the research team to have access to my anonymised responses. I understand that my name will not be linked with the research materials, and I will not be identified or identifiable in the report or reports that result from the research.

4. I agree for the anonymised data collected from me to be used in future research

5. I agree to take part in the above research project.

<table>
<thead>
<tr>
<th>Name of Participant (or legal representative)</th>
<th>Date</th>
<th>Signature</th>
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<tr>
<th>Name of person taking consent (if different from lead researcher)</th>
<th>Date</th>
<th>Signature</th>
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<tr>
<td><em>To be signed and dated in presence of the participant</em></td>
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<tr>
<th>Lead Researcher</th>
<th>Date</th>
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<td><em>To be signed and dated in presence of the participant</em></td>
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Copies: Participant Researcher

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Appendix 13

Focus Group Questions
Questions

**AOS staff:**
What do you understand by the term RSE?
Do you see a need for this to be taught to YP with ASD?
Were you aware that it becomes compulsory next year? How do you feel about this?
What topics do you see as being most important to cover and why?
How do you think AOS could support schools in this curriculum area? Is there a role for you? If so, what?

**EP:**
What do you understand by the term RSE?
Do you see a need for this to be taught to YP with ASD?
Do you see a role for the EP? If so what? If not, why not?
What topics do you see as being most important to cover and why?

**Parents:**
What do you understand by the term RSE?
For this question, I want to hear from the most hopeful part of yourself, the one that sets expectations really high for your family and your child. For this question, tell your doubtful self to go away for a while, but not too far, because we will want to talk to that part of you next. What are your hopes for the future for your child with respect to sexuality and relationships?

- What would you like your child to understand about sexuality/growing up?
- What will need to be in place for your hopes to be realized?

  What are your fears or concerns about your child’s sexuality?

- What are your concerns regarding sexual safety for your child?

Does your child have the safety skills he/she needs to be safe?

  What aspects of your child’s disability affect how you feel?
  What would help to make sexuality education seem more relevant?

What do you see as your role as a parent in teaching your child about RSE?
Are/Were you aware that RSE is being/have been delivered to your child at school? How did you find out?
Are/were you happy with the way in which RSE is/was delivered to your child?
Do you think this is a responsibility to be shared by school?
Were you aware that it becomes compulsory next year? How do you feel about this?
What is your biggest challenge as a parent with respect to your child’s sexuality?
What topics do you see as being most important/relevant to cover and why?
RSE FOR YOUNG PEOPLE WITH ASD

**Teachers:**
What do you understand by the term RSE?
Do you see a need for this to be taught to YP with ASD?
Do you see a need for RSE to be tailored to suit the needs of YP with ASD?
Do you currently teach RSE to pupils with ASD? How is it delivered?
If not, why so?
Do you use an ASD tailored programme? Why/why not?
Is it taught in whole class, groups, 1:1? Why?
How confident do you feel delivering this curriculum? Why/why not?
Were you aware that it becomes compulsory next year? How do you feel about this?
What topics do you see as being most important to cover and why?

**DEBRIEF**

**PUPILS:**

What do you understand by the term ‘Relationship and Sex education’?
Do you feel this is something that should be taught at school? Why so?

Have you received/are you receiving this education at school? Anywhere else?

Have you ever used the internet to find information about sexual issues? What did you learn/want to discover?

Do you believe you have been given the right tools and information to go on to have successful relationships?

Is there anything you feel you have not been prepared for? What could be done to prepare you better?

**DEBRIEF**

Is there anything that is of concern to anyone? Anything you would like to discuss further?

Is there anything you are unsure of with regards to the study, and would like some help with?

If you think of anything, please don’t hesitate to contact me. My contact details are on the consent form you signed.
Appendix 14

Pupil Transcript
Pupil group transcript

Question 1: What is your understanding of RSE?

I'm here at school on the 2nd of the 11th 2018 with the pupil group I've got with me Susan, Stan, Ron and Edward and we're starting off with their understanding of the term relationship and sex education. We've had a practice go, so it should be easier this time around. So with the relationship side of things, Ron you said something about your understanding.

Ron > yeah pretty much relationships is about understanding how different people like think and how to sustain relationships and keep friends and that.

Yep.

Ron > And then on the Sex Education side of it, knowing about sex education makes you more prepared for the consequences of actually doing it since it's generally taught at the age of I think… 12

Edward > Year 6

Ron > and that's kind... because puberty is what triggers the... like it generally triggers both the desire to do it and also the means to do it within your body and because of learning it then you'll understand the consequences of doing certain actions in the future which will help prepare you so you know what you're getting into so you can't say that I accidentally did this or did that.

Yep, yep. Wow. I think it helped having some time to think about that Ron. Well done. Susan?

Susan> Like…like… how you get on with pupils, like listening to their needs... and stuff.

Uh huh, good. And Stan you had an interesting take on the Sex Ed part of it. You were thinking more about the future?

Stan > Yeah the….the medical consequences of it and understanding like it's not just…. like you can have a child that can be, like…it could affect your health for the rest of your life.

And you talked about the risk of disease?

Stan > Yeah like one of them will lower your immune system so even like a common could just put you in hospital.

And you're referring specifically to HIV and AIDS, yes?

Stan > I always forget the names. Sorry.

No, no, that's fine. And Edward do you want to add anything before we move on

Edward > no
OK that was a good Icebreaker (all laugh)

Susan > Is it definitely recording?

Question 2: Should RSE be taught at school?

Yes it is. Ok so my next question was: Do you feel that this is something that should be taught at school?

All > Definitely. Oh yes.

So you're all in agreement? Why?

Ron > Well as I mentioned earlier, it's generally, it's the right age so you know what you're getting into in the future, so you don't do anything accidentally that could change your entire life. It's preparing you for what may happen.

O. Anybody else wants to add to Ron's comment?

Edward > I suppose obviously some people when they're younger, don't really notice anything, but then when they get slightly older, their voice starts dropping and everything else happens…

Ron > It's to prepare you…

Edward > It’s to prepare them, to see what's happening, see what's going on and why.

Yeah so you think it's good that schools start doing it, I think as Ron said, around age 12

Edward > Year 6

Stan mentioned Year 6. So a little before age 12 so that when these things happen it doesn't come as a total shock.

Stan > Well the physical effects will show around year 6

Question 3: A role for parents

Alright. do you think there's a role for your parents in teaching you about relationship and sex education have any of you had a discussion with your parents?

Susan > well they kind of....well it's kind of better coming from your parents cos’ you like know them a lot more and stuff and you understand how they're trying to like get it through to you. It's like, it's like when somebody you don't know tries to explain it to you it makes you like…question it kind of….

Yeah ok. Have you had your parents talk to you about ....yes? no?

Susan > Kind of.... yeah.
Ok alright. anybody else?

Ron > Uhm... My parents may not have actually talked to me about it, but I do trust in their actual judgements in general. So I think that it is alright for parents to just speak up about sex education in order to help the next generation understand it, at their own pace, because at school you kinda get rushed into it at Year 6 but when you're with your parents you can take it however fast or slow you want. So doing it with your parents may actually help you learn it more easily.

Edward > I suppose if with your parents you should also do it on your terms. So obviously like, they shouldn't just come over to you and go "oh we're going to talk about this now". It should be your choice. But with school, I find it's more awkward with your parents because obviously...yeah.

It's your parents (all laugh) It's like why are you telling me about this?

Ron > In reality it's all about personal opinion. On whether you want to do it or not.

Edward > Because then I find if you do it at school, I find it's easier for me, because you can sort of like... laugh at it in a way, with your friends which makes it better.

LSA > Can you clarify that point? Are you talking at school by Teachers or at school with friends?

Edward > With friends.

LSA > Alright. So not taught by teachers?

Question4: How it is taught at school

Ok... so you prefer to encounter sex ed through conversations with friends?

Edward > No, I mean like if in a lesson, a teacher is teaching it....

Ok

Edward > We can make ...

And then you'll have little remarks with your friends?

Edward > Yeah, which makes it a bit more comfortable.

A bit more comfortable... ok, that makes sense. Were any of you spoken to by your parents before you did it at school or was it that, when it was done at school, you mentioned it to parents and then they spoke to you about it?

Susan > Well I told my mum we were going to be told about it and then she spoke to me a bit about it before we did the lesson.

Ok Susan
Edward > I missed the lesson.

**You missed it! Oh dear.**

Edward > Yeah because the school didn't give me a letter so I weren't in that day.

**hmmm.... And how did you feel about that?**

Edward > I was quite happy to be honest.

**Ok**

Stan > all of the health lessons we missed they were going on like…. literal videos of watching stuff and I was like ‘Thank God I wasn't in the lesson’. (all laugh) It's just that they were talking about it. I'm like talk about health over this(laughing)

**Ok that brings me on to my other question then which is... have you received this at school? I know you said it started at primary school in Year 6.**

Stan > I missed it cos I moved school, so I missed it. So at my old school they did it in year… they did a quick overview of it in year 6, but then they actually went into more detail in Year 7… because obviously everyone had just moved from all different schools and I think people...well I thought they thought that people needed to actually....like.. be comfortable around other people before they start talking about this because it wasn't a school where it started From year 1 through to 6. It started at year 6 so ..... **Ok. So they tried to get everybody on an equal footing?**

Stan > yeah

Ron > I had a very opposite kind of way. I moved schools half way through year 6 but the thing is I'm reasonably sure they did it fully in Year 6 at that time if I remember correctly. And well I had already done it at my previous School then I moved and did it again

**So you had a 'double dose’ of it (all laugh). So is it then from what I'm understanding that you all did it around year 6/7 and then nothing else has happened since then**

Edward > No, we still do it.

Ron > A bit here and there it gets mentioned whenever something important related to it pops up or some new information is found out and stuff like that. It's just to prepare us kind of, because nothing is set in stone. New things are discovered almost everyday.... really

LSA > just there is a point to clarify as well. Certain Excel students might do things in here as interventions that may not be the rest of… what the school is doing.

Susan > I haven't done it since Year 7

**Ok so Susan hasn't done it since year 7**
Stan > Well lucky all of you (all laugh)

When last have you had it Stan?

Stan > ummmm..... Well we did it in biology a bit, only because… just… like I, I had to do it because I went in for… I did work experience with the science department and unfortunately I dragged myself into a biology class and I was like "God we're doing this again" so then I was actually having to teach...

Edward > kids about it...

Stan > yeah...your year as well...(all laughing) so it was a bit ....and then they saw me round School and I was like...

Just curious what year are you in at the moment?

Stan > 11

Year 11. Ok

Stan > I was in year 10 at that point so...

hmmm ok. So you were involved in helping to deliver relationship and sex education. That’s interesting.

Stan > Yeah (laughing)

LSA (to Susan) you said you've not had any. You look like you were going to say something. Is that what you wanted to say? (Susan nodded)

So Susan said not since year 7. Ron when last did you ....

Ron > uhhmmm.... I don't clearly remember but I think around Year 7 as well.

Edward > Yeah…we cover it at certain times. It's just like I'd rather do a couple of weeks on it every year than we do at school.

And what year are you in now? Year 9?

Edward > yeah.

And Ron what year are you in?

Ron > 10

Edward > We did a full topic in the year 7

LSA > Sometimes we do it on a Tuesday morning which not all our Excel kids go to form. Do they do it in form on a Tuesday morning? Is that what you're all about?
Stan > PSHE is normally on a Tuesday.

LSA > And they stay with their form group but because our lads, they don't always go in to form group.

So will there be another opportunity for them to..

LSA > We cover that to varying degrees within Excel depending on what a student needed.

Ok alright.

Stan > I think the way it's taught is changed… since I was taught it though,

because obviously it's…

Tell me about that

Stan > The GCSEs have changed as well. But obviously I was taught it…6 and 7… 6 was a curriculum review, 7 was the full topic, but it was more on… like what each body parts does and then I believe year 8, year 9 was going into detail about a different like… consequences, like the diseases you can catch. And then we're learning about…like now in biology ummm we are learning about like how… like the different .... I can't remember what it's called....

mmmm….. Min-strals cycle?

Susan/LSA > Menstrual cycle

Stan > That's it. Minstrals the … chocolate, innit? (all laugh)

(laughing) That's fine

Stan > But like all the different cycles and like the ways around someone that can't have kids so it's, it's… I think it has changed since I was where you guys are (referring to others in group) because it's still being taught now and obviously you haven't learnt it since.....7

So is that a good thing you think? Extending it?

Stan > Well... so for what I want to do… when I'm older, yes. But for other people who have no interest in it {(whispers) which I find quite heart-breaking, the science part of it by the way, I found quite heartbreaking} but it's just like they don't really...

Care too much for it…?

Stan > like they, like obviously, because they have to learn, learn it. But obviously they're not taking full… like… interest in it….if you know what I mean.

Question 5: What to teach?

Ok that's a really good point and it brings me on to one of my other questions this one was on your questionnaire as well. What kind of topics do you think would be good to include in a programme of relationship and sex education?
Ron > uhm...

So on here (the questionnaire) I had: Making and keeping friends - some people weren't sure about that one?

Edward > I think all the topics are good but I don't think the actual sex part is a good topic to teach until you're older.

Good point Edward. Yes Ron?

Ron > Well pretty much I think all of them are important in their own way. Like they can all be taught. Is it more like how... so it's more like HOW it's taught instead of WHAT in it is taught. You should, I think you should just include as much as possible because it's just this one off thing and once you finished it then you can pretty much...if you do it over a long period of time it's just coming back to it over and over again and if you do it all in one sweep, then it's a lot more comfortable kind of because you know like, after today it's over and so... well... apart from... in the actual biology part of GCSE and such

Stan > Yeah I have to do this probably again and again and again and again (laughing)

Question 6: How to teach?

So I just want to pick up on something you said there Ron. Are you saying that you think it's best to do it 'all-in-one sweep' to use your words around year 7 and then it's over? Or would you prefer if it was kind of drip fed. - a bit in the year 7? a little bit more in year 8? a little bit more in year 9?

Ron > Uhm...I think it's nice to get it all done and dusted in one go because most people find this topic uncomfortable generally, so it it would be best to just sweep it all under the rug as soon as possible.

Do we all agree with that? Edward?

Edward > I disagree with your comments though. When you're in the year 7 you're at that immature age where you are just going to mess around and not take any of it in. So if you just do it all in one go, all in Year 7, none of it's been taken in.

Ok so are you suggesting...

Edward > A little bit each year but not too long.

Alright. ok. What do you think Susan?

Susan > I was going to say like.. so like carrying on from what's Calum said a bit, so like... when so like, in the younger years and stuff you should do more about like friends and relationships and stuff and when you get into the later years you should do more about like....

Ron > The sexual parts

Susan > Yes
That's a good point. Yes Stan?

Stan > Me being me (laughing), and having to be the opposite, ahmmm, if you're going to do it all in one go, uhm, considering that I'm still learning about it after 6 years from when I actually started it, it's gonna like probably need more than one lesson every two weeks as well. But like again, agreeing with the part that Susan said, like to more or less ease into it, instead of like, just go straight into it....yeah.

Alright so we have different opinions there. That's absolutely fine.

LSA > That might be as well because we have a 2 week time table. So I think the two week timetable thing could make a difference. If you knew you were doing something once a week, every week, that may change…

Make a difference. Hmmm.... Ok on here (referring to questionnaire) I had ‘Making and keeping friends, Safe sex, Contraception, Consent- giving your consensual agreement to do something and Dating’. Were there any other topics that anybody else thought of that might be good to include? (Quiet. Thinking) Does that pretty much cover it, you think? Ok

Edward > uhh... I have a quick one. ahmm... Generalized talking to people on the phones and just talking to people in general because nowadays, you start teaching a language because everyone keeps making up new words no one understands. Shortening words on phones, needs to be taught in lessons.

Ok so maybe like a vocabulary of different words....

Edward > Yeah

For Different things and what they mean?

Ron > Yeah

LSA > And situations we've done work on how to talk to girls on the phone because you interact differently and there are different expectations

Stan > People are lot more open behind the screens as well so like it's ok talking face to face with someone about their feelings but like…. especially like with guys, they find it a lot easier to like talk to another person about their feelings behind the screen.

Hmmm...That's interesting Stan

LSA > And I don't know whether that comes within the term sexting? Have you heard of that word? (to the group) yeah?

Hmmm...that could be something that could be included as well, yeah. Ok have any of you, as you've mentioned sexting, have any of you ever used the internet to find out information about sexual issues?

All > No
Stan > No. Other than biology homework.

Ok Stan. Biology homework, alright.

Stan > Because I'm that sad nerd that actually does science homework (laughing)

Ron > I only have double science but I do do all my homework so it is understandable that some people have and that would be just awkward…

*Ok let's talk a little bit about question 9 On your questionnaire. Which was about the best way to go about delivering: ‘Small groups and not in class with everyone else’ Some people agree, some people disagree. What's your opinion on that? Do you prefer to stay in class with everybody else or to come out, maybe in Excel and do it in a little group?*

Edward > I don't mind…uhm.. either way. I find in small groups it's fine, but big groups it doesn't make any difference at all. Of course it's easier to teach in a big group plus you can talk to all your mates and stuff there in class about it. You can talk to the other gender about it… just general…

*So it doesn't really matter for you?*

Edward > no

Ok anybody else?

Susan > I will find it easier if it's like all one sex getting taught about it.

Ok so like girls alone?

Susan > Yeah because if they were boys in the class I'd kind of find it awkward trying to like…..

*Yes, yes that's understandable.*

Stan > I guess it depends on the person itself like what they are like, whether they want to…because obviously me, I was…like I literally look like a weirdo because I was interested in the biology part of it right and it's… it's cos’ like obviously an embryo is starting from a single cell and then it turns into a human body and it’s from one cell itself. So I was interested in that, so I was paying attention and I just look like a right weirdo. So I guess it depends on the person whether you actually want to… like pay attention but not look like you're paying attention because obviously you're gonna get ‘finished’.

LSA >But it's ok to be interested in sex and the mechanics of it and understand it all but…

Stan > It's just what people look like…yeah

LSA > But you might feel embarrassed about asking questions or looking interested because then you might look like you don't know anything
Stan > Because, because I was the person who was at the back of the room just writing everything down, trying to do everything.

Ok so are you saying then that for you, you may have preferred to be out of class? Or you are happy being in class...?

Stan > Yeah because...

Or in a smaller group?

Stan > Because there was a lot of teachers stopping, telling them to be quiet, stop laughing and I was just like (whispering)"oh my gosh I just can't ...please, don't make my parents…”

Ok what about you Ron? What would work best for you? in class? in a small group?

Ron > I would rather just do it. Ok. I don't really mind either way. I can do it any way because either way it's just...you're learning the same thing really, so it's no less awkward whether you're in umm.. mixed class, small group or large group, or literal individual. BUT this is something different - What if you could actually like, split up, like what if an actual student chose some small groups, like with their friends and such who they felt comfortable around to learn it with... so you learn it that way.

Oh ok. That's an interesting take. So they choose a group and then its taught to them within a group of their choice?

Ron > Yeah.

Edward > The only problem with that is the fact that some people will just pick a group where they can literally just mess around and wind up the whole class and it just wouldn't work.

Hmmm...so that's something to consider.

Susan > I guess if they were in a separate group then they will be with other people who actually wanted to learn about, about it.

LSA > But you know like, if you...I'm just thinking, thinking about a group of friends. You've got, you got a group of boys, and it is embarrassing anyway isn't it, and one of them decides to mess about, they’re kind of disrupting it for everybody, even if within that friendship group

Edward > The other reason is that you can't have 5 different rooms for like your whole class to be split up in different rooms and then you'd need 5 teachers as well.

Yes.

LSA > But they could do it where you carry on normal lessons and the small group gets taken out every week and alternate it with a different person and taught it that way.
Stan > Like the old interviews they used to do at my old school

LSA > It could be an Intervention rather than a lesson

So would you prefer if it was done in that kind of way?

Edward > I am not bothered

Yeah, not bothered? Ok agreement around the table then that you're not too bothered. What about open discussion? Do you prefer someone just talking at you or would you prefer an opportunity to discuss things?

Ron > Well, if you talk about it, then you can actually discuss it as a whole class. So then everyone can voice their own opinion equally, say their own opinion. It does have a chance of there being disruption, but at the same time, it also really just... it will help, because like... in my year all of us like, or entire year, generally in year 9, it kind of is organised into groups and such and everyone's come around each other so it's more or less just generally... if we went in talked about it openly, then everyone will have their own voice to share and then you probably learn about it more efficiently since everyone would be asking questions and adding more and there would be....

Ok so you think having more open discussions....


Edward > I agree.

I know Susan you said before you prefer girls separate, boys separate. How did the boys feel about that? Would you prefer separate gender? mixed gender?

Edward > Actually it would be easier having them split because I find the girls generally gets more embarrassed than the boys do about it.

LSA > do they?

Edward > Yeah I’d say they do.

Alright Edward. Stan do you want to add anything?

Stan > Like, if you like, say if like, they had a choice in like, if they were given the topics that they were taught like, if they had a choice when they were going to be taught it.

Ok

Stan > So they knew when they were going to be taught it so...

So they knew beforehand...what to expect going in to the lesson...
Stan: Yeah, so they can organise the timetable of what they were going to be taught instead of it being like, “So today we're going to learn this…”

**So it doesn't just land on you unexpectedly. Ok.**

LSA: Do you think that some subjects should be taught separately like the biology if you were looking at genitals or whatever, and then, that could be taught single sex. But if you were doing something like uhm…. contraception, maybe that might be better in a mixed group where you've got points of views that could be raised. You know like a girl may say something about contraception that a boy might not realise?

Edward: I think everyone’s take is different.

LSA: Exactly and there’s different points of view, isn’t there? So maybe there's a case for some of it to be done all in different ways.

Stan: yeah but saying that is like like…. Like… all more less embarrassing (to himself – ‘that makes no sense’) or less embarrassing than that but then like then it will just be the girls are only learning about the girls area of that part when you need to learn about both.

LSA: But you can have, you can have it so that it's maybe tailored in different ways so maybe the boys don't need to know in as much detail as the girls. So the boys could still have that information but maybe it's… there are, there are certain aspects of personal care that men may not need to know and just...

Stan: But then like most. most of like that area is taught in science and again you need to learn that for your GCSEs and further exams so it doesn't just have to be what you’re going to be, it has to be taught because it could be one of the questions so it can't… you need to know as much detail about us both.

Edward: Yeah, because they’re not going to change the syllabus…..

Stan: Yeah they can’t change…

Edward: For each gender.

Susan: Personally, I would find it easier. Like even if, like we still would learn about like… stuff with boys and stuff ….but I would find it easier just with girls because if the boys were there…. I just feel awkward.

**Ok that's clear. Ok what about the gender of the teacher doing it?**

Ron: I don't think it really affects…..

Stan: Yeah the teachers just act like it doesn't matter anyway.

**Ok and for you Susan it doesn't matter either?**

Susan: No not really, no
Sure?

Susan > Yeah.

LSA > So if a guy, if a male teacher was going to teach you about female genitalia or periods or something like that, will that be better or more awkward do you think?

Susan > Well I feel like it will be less awkward with a woman, but with a male teacher it would just be like a teacher teaching.

Hmmm..

Stan > It depends on their profession I think because most ....

LSA > So you mean like if it was a science teacher? Is that what you mean?

Susan > Yeah

Stan > So like say for PSHE, instead of having your form tutor explain it, whilst they know their form, they have laughs with their form, they will have like, like an actual person that teaches that area, so it's like, it's taught properly instead of like your form tutor just having a laugh because our form tutor just ..... You wouldn't want your form tutor teaching it...?

Stan > No we just have giggles with a form tutor.

Question 6: other areas to address

Ok We are almost there. Is there anything regarding relationships and sex education that you feel you have not been prepared for?

Ron > No. I feel like we've been prepared with everything we need to know.

Susan > Yeah.

Ok Ron so you feel you know what you need to know?

LSA > (to Stan) you're probably the best one to answer that

Stan > Again, things have changed since I was taught because you said you're in year 9 now and you haven't learnt it since Year 7, but I...I’m still going. I'm still learning it now and I know whether that's because of the options that I took, or the teachers have picked up on the science part but it’s a bit different so...

Ok but generally you feel you know what you need to know? There's no area of it where you are thinking "oh, I wish they had taught us more about that"?

Susan > I feel like we have learnt about like how it all works and stuff, but we haven't really learnt how to like … ap-pr-oach it like say....
hmmm hmmm

Stan > Do you mean like when it gets to that situation...

Susan > Yeah…. like how to deal with it and stuff

Yeah ok

Edward > That's because they never really teach that side of it. They teach the biology of it.

Stan > Yeah that's going to be awkward for anybody.

Susan > They just teach this is what girls have got and this is what boys have got and that's it.

LSA > Whereas we might do something like that more in here, within you know, Excel department.

Ok, so to be more specific, things like how to go on a date with someone.. ... 

All > Yeah

That kind of thing?

All > Yeah

How to decide when to have sex?

All > Yeah.

And when not. Ok. Alright, so you think those are areas where you probably need covering better

All > Yeah

Edward > Yeah I suppose things like just asking a girl when to go on a date with her.

Stan > because as well as learning about it, you can't just like go off and do it. It's, it's gotta get to that point you can't just like... And then like how to approach when it does get to the point. It's going to be awkward like...

Susan > Yeah and how to notice when the other person is like….

Stan > Ready

Susan > Yeah

Those are really good points and I think I'm going to wrap up here because it's your break time. You have been really, really helpful and I'm going to stop recording now.
Stan > (After recording was stopped) I was just thinking of something else that could be taught. We could include more on homosexuality. Like LGBTQ material. This was touched on but in too much detail.
Appendix 15

Parent Transcript
Parent transcript

Question 1: What is your understanding of relationship and sex education?

Ok so it’s the 1st of November 2018 and I’m here with the parent group. So my first question out to all of you is, what is your understanding, as parents, of the term relationship and sex education? Anyone wants to have a go? What do you think about when you hear the term relationship and sex education?

Beth: Preparation for school kids, and well kids of any age, so they can have a stable, secure, safe, relationship in the future and uhmm, not run into difficulties like learning from people who have had those problems. As a starting point.....

Ok anybody else?

Julia: My memory of it is all being grouped together in a massive school hall, and the deputy headmistress holding up different bits of contraceptives, and yeah and no one being able to really get much from it. So, uhh..., how it’s taught in schools nowadays, I have no idea.

Hopefully it’s not like that! (All Laugh)

John: I had to put a condom on a banana (All laugh)

Sam: so uhmm my understanding, from what my son did last year, is uhmm a little bit about all the different words, slang words and what they all mean, so that there is not so much confusion. Uhmm, for example, I distinctly remember uhmm, my son’s dad ringing me up last year saying: I just picked him up from school and he said ‘Daddy I know what a pussy is’ (all laugh) and I and I said ‘alright’, and he said: What’s he talking about? And I said, ‘Well I think he’s had sexual education today. I said, ‘did you talk to him about it?’ And he said, ‘No. I rang you straight away’. I said ‘ok’ (laughter). I said ‘ok’. I said, ‘well why didn’t you ask him?’ So he says, ‘why did, why are you talking about that?’ and my son said ‘Because we’ve been doing sex education at school today.’ He said, ‘Well how do you know that word?’ He said, ‘Because everyone was shouting out, was asked to say out loud all the different words, and that was one of them.’ He said, ‘And I know what it is now.’ And well we’ll I said to him, I said, ‘Well there you go. That’s what the answer is.’ And he said, ‘Well NOBODY asked me about this. I am NOT happy. He’s my son. I should be educating him about all this. He’s too young to know.’ And I said, ‘Ok. But from my point of view I’m really glad he’s done this, in this environment, with other children his own age, and he will now not be confused by these words that are banded around the playground. He knows what it means.’

What was too young? How old was he at the time?

Sam: He was 10.
So Dad thought it was too young. How, how did you feel about that age?

Sam > I was fine with that. If they're all talking about it on the playground 'cos it was them who gave the words, if they're all talking about it and my son perhaps might have been the only one who didn't know, who didn't get the joke and didn't understand, he's being isolated by not knowing. But now him knowing, just means that he knows, doesn't it? And he's not feeling that way anymore like he's not aware and he can't ask. He probably would feel that he couldn't ask anyone about it and it's probably, you know. I said to my, his dad, 'It's probably a good time to have a conversation about it. It's in his mind, he's telling you that he's learnt about it, so take the opportunity and tell him now what you want him to know, and use the opportunity really.

So how do the rest of you feel about age 10 as an age to start? Do we think that's a good age? It's too young? It's too old?

Beth > I think little by little is quite good, with a bit more information each time. It's like anything you learn, you know, you don't learn French with everything at the beginning. You learn first how to talk about your holidays this way, and then a bit more, and I think sex education is learnt the same honestly.

Jade > My, so my son is 6, almost 7, and because he's got an older brother I think we have, have talked about it because the older one has brought things up. And again with different words, you know, and he comes home and says 'I know these new words' and I try not to be, you know, phased by that I guess because you know, because exactly, I don't want him to be on the back foot when he is, you know. So what, what I'm saying is that my 6 year old is in on that conversation. He's not initiating them, but he's in on them and I feel really happy with that for the same reason as Beth, you know, you're kind of drip feeding. He's picking up little things. And he knows it's not a taboo subject and I am not phased by those questions. And I laugh when they laugh because it kind of is funny and I don't, I don't feel you know.

So the way you reacted will have a lot to do with how he responds?

Jade > yes

Do you want to add anything John?

John > yeah I think it's about, it's about trying to yeah, take the taboo away from these terms to make it very clear that these are topics we can talk about naturally. And that doesn't mean that everything is age appropriate, but equally, I don't feel there is a cut off age at which you should first start the subject. I think it's a natural part of the language that they hear. And it's on their mind to a degree, and I think parents just normally want to go with that to help, help the children out and not to look like we're shocked or dismayed or upset by that as far as possible because that probably would have the adverse reaction.

Jade > I'm sure we've all been relieved to get home from a car journey when they're asking questions like where do babies come from it's like "Thank God we're home now" (All
Laugh). My son laughed at me when I said people enjoyed it and we all laughed all the way home. He said ‘you’re joking!’ I said, ‘No. Just wait about 10 years!’ (all laugh)

**Question 2: Hopes for the future**

Ok, for the next question I want to hear from the most hopeful parts of yourself the one that sets expectations really high for your family and your child. For this question tell your doubtful self to go away for a while. But not too far because we want to talk so that part of you next what are your hopes of the future for your child with respect to sexuality and relationships?

Sam > I just hope he gets what he’s looking for. I know he really wants children, already he keeps telling me. He understands that he needs to have a wife to have children and that’s it really, just for whatever he wants, to be what he gets. It’s just that simple for me.

Ok anybody else wants to share?

Julia > I really hope Bob can work out some of the intricacies around relationships that I don’t think we are ever educated about. As I say, sex education was condoms and bananas and all that kind of thing and sexually transmitted diseases. It wasn’t about understanding different people’s emotions, which is what Bob is going to find really really difficult.

I think you’ll be happy to know it’s not like that anymore we’ve moved on a bit from that now and with regards to the new curriculum that’s coming in next year making it compulsory, there is an emphasis on the relationship side. Actually through primary school they should focus on the relationships, making and keeping friends and that kind of thing, and then by the time we do get to secondary school, there will be the sex bit of it. Hence the reason it is called ‘Relationship and sex education’. So relationship first, putting the emphasis on relationships. So that’s where it’s heading. Would anybody else want to talk about their hopes for their young person?

Jade > Yeah. I hope that he understands more than the mechanics of this and that he um, that he feels sort of free to experiment. But I want him to have the kind of moral uhmmm...attached to it.

A moral compass?

Jade > A compass. Yes, exactly. And that he knows the kind of, the benefits and the, the opposite of benefits... can’t think of the words (laughs)

The pitfalls...

Jade > yeah. And that we can just talk about any of that and that you know, no shame. Yeah opportunities to say what he wants. I told him the other day you know, I said men can marry men now as well. Women can marry women. And he said ‘Really?!’ you know, (laughs) I said, ‘yeah’, you know, and I kind of just want this to be kind of normal and for him to be humane, kind of.
And how old is your little one?

Jade > He's almost 7.

Oh yes you said he was 6 when.... ok almost 7 now. Ok anybody else, Beth?

Beth > for me a lot of the conversation has been about learning about respect and trust before you take anything too far he doesn't recognise all the signals people might be giving like it's really not fine to do that with friends around and don't push people too far because he is and we talk about how he doesn't necessarily understand how other people are feeling so that's going to be more difficult It's Tricky cos a) he's a guy and b) he's autistic so it's difficult for him to read the situation and we joke about it like that but he's got, you know, it's going to be difficult but everything has got to build up gradually so that he doesn't lose friends along the way. He has had some crushes and yeah (laughs)

Ok so your most hopeful self would wish for him to be....

Beth > to be happy in a respectful trustful relationship, if that's what he wants. If he's on his own that's also fine. It's to know that we support him whatever type of relationship it is. That's what really matters to me.

John > Yeah. I don't think there's such a thing as 'normal', sex wise really. And I think I want him to have a normal approach to relationships in the sense that I think they'll find all the kinds of challenges and opportunities that every young person feels. But I just want him to not get fixated with what's normal and what isn't normal, and to cope, and that they prioritise relationships – trust, respect, and that they prioritise friendship. And that you know, they have lots of warm and stable relationships where they're giving and receiving, and care, and respect, and that's my sincere hope.

Julia > can we talk about consent as well actually because I think again with the autism, I...there's been times when he doesn't know when to not you know, kind of climb on someone or you know and he...he...I would just say, if someone says 'I don't like that, you know, you just...no. No, no. you know and I kept thinking 'actually this is very positive message you are sending out'. If someone says no, they mean no immediately and you just need to back off however you're feeling. This is not about you this is about the other person and I felt quite pleased that actually we can now we can transfer that in the future into other things like sexual consent.

I think that's one of the topics that would be covered at primary level just simple ways of giving consent ok what would you like your child understand about sexuality growing up. I think we touched on that a bit I know John you were saying that you'd like to stress that there's no normal as long as he's happy and the person he's with is treating him right and that kind of thing anybody else anything you would like your child to know. I know you said 'consent'. Anything else you can think of that's really important you feel for your child around sexuality?

Sam > I suppose just knowing the different kinds of relationships there are and that they are all....fine.
Julia > My daughter brought home her girlfriend for the first time 3 weeks ago, that kind of time. And Jack, it's, it's just normal and nothing can.... in their world it's probably more normal.

Sam > Yeah I've got one of my old housemate's who lives not far from us and got married last year. And we know them really well and Joshua thinks it's ok to keep going, ‘Hello wife and wife’. You know, he thinks it's really funny. And my best friend's, husband's best friend is gay and he's married his husband this summer. So he thinks it's really, really funny now to do the ‘husband husband’ thing. But we spend a lot of time over there because they've got children his age so we spend weekends with them and stuff like that and they're around them all the time. So I think it's quite normal for him.

So again back to John and accepting that there's no 'normal' really?

Julia > But diversity is normal, and it links to the new neurodiversity thing, isn't it? Is we're all diverse in the way our brains work and we're all diverse in what we choose to do for pleasure.

And how we see, feel, and how we think.

Beth > what I think was said and what we started talking about a little bit about the kind of feelings and having gay feelings and whatever. I think it really doesn't matter whatever, we've got loads of gay friends and he hadn't actually really twigged that is Godmother who stayed with her, her partner and we have loads of gay friends who stay with us and he really hasn't paid because we haven't really made a deal of it they just like here comes Asha and Holly it's fine but he hadn't recognise actually and that's quite a big help for him that we pointed out that it's like " Oh... right! Loads of people then". We hadn't made a deal of it and I wish maybe I had (laughs) because it would have helped him you always think you can do better don't you. That's what you tell yourself.

Question 3: Fears for the future

Ok do you have any fears or concerns for your children with regards to their sexual safety for example anything like that? Or maybe you've never given her thought?

Beth > The vulnerability is actually a huge fear for me, because he wants to know if somebody is taking advantage, or pushing him into a situation to get him into trouble, cos other kids can manipulate and he doesn’t realise... yeah.

Sam > He wouldn't realise that someone was trying to manipulate them. So yeah, exactly the same.

Do we all agree with that? Julia?

Julia > Yeah . And how to make that a realisation but not a scary realisation. Because nobody wants to feel they’re vulnerable and... and rather...there's got to be a way to make it less... I don't know what I mean I can't find the right words for that one (laughs) kind of building up really good friendships that you really trust... not fake friends
I think one thing actually that I'm slightly worried about...I feel like I know quite a few people who've actually realised that they are autistic as adults, and they've kind of had relationships and it's never the autism has never been out there. And so I think, you know, my sister is my good friend as you know, and that's actually the fact that he knows or he will know, cos I don't think he knows he's autistic yet. But because we don't talk about it like that. But if he, if he somehow thinks that's a barrier, that kind of sometimes I think he is, it's better, I don't know, for it not to be known. I don't want him to just keep thinking he's different and no one will like him, or because we, because he knows he's autistic or he will, when, you know, he wants to start a relationship. And yeah, that's a, that's a funny one. So lots of people discovering it's almost like, it's not an issue you know, they get like they've been married 25 years and suddenly like yeah, I think you're autistic. You know and that almost seems like yeah, you know, it doesn't really matter. It doesn't matter when you can have a relationship with...you're a human, you're as human as anyone else....

Beth > Quirkiness is very attractive sometimes (All laugh)

Jade > That is true actually. Yeah I know what you mean I think he might be very popular actually my son (all laugh)

John > I worry, and I don't know if this is anywhere specific to having an autistic son, but I just worry that all these things are happening at the moment when he is least likely to take guidance from his parents.

How old is your child?

John > he's 6 and a half old....hopefully a way off yet. But it's that thought, you know, that his sexual urge is going to reach it's peak at the very point at which you're trying to loosen all the ties from home, and parental authority. And that's nervous because I want there to be people who he's close to in his life; who he will listen to at the point where he might not be that as willing to listen to me. And so I feel like I want to do the ground work now, almost to help him to have good other relationships in place with peers and with adults, so that even if mum and dad aren't his best friends at the time, you know, there will be other people whom he can trust and call on.

Sam > like cousins and stuff

John > Yeah.

Question 4: Parents Role

Ok. What do you see as your role as a parents in teaching your child about relationships and sex education?
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Julia > I feel like it’s a 100% my responsibility. And you know, I feel like I’ve been on it, you know, with both my children, even with, you know, my son who isn't autistic. You know I, I just want to talk about it. Whenever they want to talk about it, I will talk about it, you know. We’ve had, yeah, the odd conversation in the car and we'd roll with laughter when I said, ‘Do you know people like having sex?’ And you know I think, yeah, I just want it to be embedded into everything. I just want to, I feel, I feel extremely responsible.

OK. That's great anybody else would like to share?

Beth > I admire that. I'm not sure I can say I have the same commitment to it, but I have to say, I have talked quite much.... about the relationships. I've talked tons about it because I'm the only female in the family, so I feel very much my side is the sensitive part. I think that's my role. Massively. Still working on my husband but you know... (laughs)

And how old is your child?

Beth > He's 15. And he's got a younger and older brother 16 and 13. So you know in a group, actually, it sometimes happens while we're just chatting.

And that's easier?

Beth > Yeah.

So for you it’s a little bit uncomfortable?

Beth > I think it's a bit compartmentalised for me. So for me it really is the emotional side and actually not so much the physical side.

Alright anybody else wants to share? How do you see your role?

Sam > I feel under pressure to be approachable it’s a bit what you were saying... I don’t want to ever say anything that's going to make him think "oh I'm not going to ask her anything about that again". Because at the moment we’re lovely do you know what I mean he can he will ask me and I'm I'm quite happy I was a little bit uncomfortable but I'm very happy now I'm very happy with anything he’s saying and I just hope I hope I don't ever have that reaction where he's going to get all "I better not ask again" and that's what I fear I'm going to do I'm going to I'm going to close the lines of communication

You want to keep the lines of communication open so that he always comes to you?

Sam > Exactly because he lives with me and the closest person to him and yeah I just I fear that about, about me I think that's the thing I'm most worried about doing but uhm but I don't know how to control that because my reaction will be what's my reaction will be

Yeah it’s a difficult one. So are we all in general agreeing then that as parents you have a part to play in teaching your child first and foremost?

All > Yeah. Oh yeah.
Do you feel the responsibility is more on you than, let's say school?

All > Oh yeah. Definitely.

Beth > I want it to be more of me.

All > Oh yeah

Beth > I don't want them telling him things that I...

Sam > it's like my son's dad when I told you the story.

All > Yeah.

Sam > It's like no, this is up to me.

Julia > I'm slightly concerned about it because I feel being high functioning autistic myself, I haven't got some of the skills that I want to be able to have my son doing. So I agree. Yes, as a parent, it's completely my responsibility. But sometimes I worry I'm seeing this from my perspective whereas I can't see it from a neuro-typical perspective. And sometimes it will be nice to feel that somebody else was there putting some input in.

Ok

Julia > But you can manufacture that to be happening. You know, like 'mentory' type people whom I will be wanting to...I want other people to get involved. But I just mean, I feel, might feel responsible that I do get people. I don't think I can do it all. Perhaps I need to clarify. I don't think it's all down to me. I think it might be down to me to engineer situations so that if he doesn't want to tell me, you don't have to tell me. There'll be somebody, somewhere whom he can talk to.

Yes, I know. When I did it at a high school, we contacted parents in the first instance and informed them of what we were doing and they had to give consent. And along with that information was a copy of some of the curriculum we were going to follow. One or two parents were a bit uncomfortable, just like the TA was, and they withdrew their children but most of them were happy that it is being done because whilst they felt they needed to do something, they were unsure exactly what to do and how to do about it. I don't know if you share that same feeling and how would you feel if it was being done in school, but in that kind of way? Like you were fully informed when it was going to happen, who was delivering it, you were given the opportunity to call and ask for more information. Would that make it easier?

Julia > Well I was going to say that even if I disagreed with it, I would want it to happen so that we can have an opportunity for me to say 'oh did they think that?' You know some people think .laughs

Julia > Exactly..... Just to kick start for someone to start it off and then I can throw in the things they haven't heard. Yeah.
Sam > I think it would be more helpful if they perhaps published what they taught like a personal email or something so we can actually read it and we can go, ‘Ok’. And we can pop it into conversation or we can say, ‘Ok, I understand you did this today. Do you want to talk about it? Is there anything you didn’t understand? What about this?’ So it would have been really good from our point of view and I think from my son’s dad’s point of view for him to have known what had been discussed.

John > Yeah. I agree, yeah.

Beth > Something about the content yeah

So I’ve just got a signal from Kevin that we need to wrap up. So I’m just looking through the other questions that I wanted to ask and I think we’ve touched on mostly everything else. So thank you very much everybody.
Appendix 16

Staff Transcripts
Interview with SENCO 1 - Carrie

*So Carrie, what do you understand by the term relationship and sex education?*

Carrie > For all pupils? Or ASD pupils?

*Generally speaking*

Carrie > Uhm... understanding about consent would be probably a biggie for my understanding that what is acceptable and what isn’t within a relationship, uhm... ages, so legal ages, uhm... and understanding about things like contraception. What.....behaviour is ok and what isn’t, when a child needs to stop what’s happening and how to stop what’s happening, and the difference between different types of relationships. So you know, you’ve got your family, you’ve got your friends and then anything outside of that as far as a loving relationship goes, or sexual relationship.....

*Ok....*

Carrie > is that ok?

Yeah. That was quite a comprehensive answer. You touched on a lot of different topics within the RSE curriculum there. Uhm... we’d talk a bit more about that later on. But I’m glad that you also mentioned the relationship side of things and about knowing the differences in relationships – a friendship as opposed to something more....

Carrie > Hmm...We use a circle that goes out and on the inside you’ve got your really close people and then we explain to children how the people that are less important are on the outer circles

*Ok. Good. Now with particular regard to young people with ASD, do you see a need for RSE to be taught to them in a slightly different way?*

Carrie > Yes, without a doubt.

*Ok. And how do you do that here at this school?*

Carrie > So we work with a group of year...we do it in year 8 and mainly in year 9 when it comes to sex ed. We do relationships and social skills in Year 7 and 8. And then sex ed we use a specific programme which was advised by Autism Outreach and I’m trying to think of the name.... It’s a huge folder and it’s very visual. It’s broken down into topics, it’s very clear. And so within our school we take a small group of...I think it’s 5 in Year 9 out of tutor time once per week and they work with the teaching assistant who works through the programme. In the past I’ve done it and it gives them the opportunity to open up about things they want to ask but will feel very embarrassed to ask. And it makes it very visual, it’s very practical – we use real objects rather than fake. So, we’ll use a proper condom. Obviously on a fake penis (laughing) That would get a bit awkward! And uhm...contraception, we use actual contraceptive devices and...we make it really tailored to
the individual’s needs. And the group that we ran they needed a very, very, very basic approach. The group that’s running now needs something a little bit more detailed. They’re a bit brighter, a little bit more ‘with it’ whereas the previous group we really needed to talk about the basics.

Alright, so it’s tailored depending on the children within the group...

Carrie > Always. Always

Are these children ever left within the mainstream class at all for any of the mainstream RSE lessons?

Carrie > Well...it depends when they’re run and I’m not sure when the curriculum for RSE....I think it is run on a Wednesday lesson 1 which is when we take them out so...uhm....but I’m sure there’s another lesson, sorry to be vague, in year 9, uhm...where they do it outside of tutor time.

Ok so there’s also some opportunity for them to get it within the mainstream as well

Carrie > Yes, yes.

So your sessions just allow for further explanation and exploration of anything with which they may be a bit fuzzy....

Carrie > hmmm yeah and also as long as you’ve got the right relationships within the group, because there are some individuals we can’t involve, and they may have their sessions sort of on a 1:1 because they wouldn’t cope with the group setting. They may take it outside of the group as well. And the children like this we tend to give a 1:1 session to.

Ok, lovely. So that kind of answered my other question which was if there was a need to tailor it to suit the needs of the young people ...

Carrie > yeah

It also touched on my fourth question, do you currently teach RSE to pupils with ASD and how is it delivered....

Carrie > Well I don’t but I set it up and the teaching assistants deliver. So we do uh... something called a friendship group in Year 7 which is a programme that one of our teaching assistants has been following for quite a number of years. It’s adapted each year. Originally it was from Autism Outreach so it’s something that’s really about friendships, relationships, how we socialise, how we make friends, how we keep friends. In year 8 we do again a specific programme which is similar, same author as the one we deliver in year 9. So Year 8 we do, we just call it sort of social skills and we up it slightly. So we talk in a little more depth, we get children to go off and do things and come back and feed back, you know, ‘did that work? Didn’t it work?’ And these are children who are quite socially isolated.


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95  _Ok so that’s more focussing on the relationships...._

96  Carrie > It’s more on the relationships but it’s also on things like hygiene and the importance
97  of being clean in order to keep friendships because there are things that can stop people
98  wanting to be your friend, as simple as that can you believe it, but it’s true. And then in year
99  9 we deliver the one I was talking about which is not just focused on sex but on the
100  changing ...the way our bodies are changing. So I think the last lesson was focused on wet
101  dreams because the boys, it’s all boys. That’s the other thing that’s important to
102  understand, it’s very rarely girls with autism that we include cause we don’t have, we have 1
103  girl who is being investigated for autism so no diagnosis. Uhm...
104
105  _And does that pose a problem, being all boys and led by a female?_

106  Carrie > Ah yes that’s been an issue in the past and it’s something we’ve discussed in detail.
107  Uhm... the reason we’ve got a female delivering it is because she is the key worker to a few
108  of them in there. She’s got a very good relationship with them and they feel comfortable
109  with her. She’s also comfortable delivering it. She has questioned whether there needs to
110  be another member of staff in there but when we looked at that, we felt that that would
111  change the trust and dynamics a little bit so she’s happy to carry on. However, the head of
112  PSHE (Male teacher) is coming in to talk to the boys about things she can’t answer, so one of
113  the questions was ‘what does a wet dream feel like?’ because there’s a couple of boys who
114  haven’t had one or don’t know that they’ve had one maybe, and uh.... Uhm...
115
116  _So he’s going to accompany..._

117  Carrie > He’s yeah... to see if he could shed a little more light on it because obviously it’s not
118  something a female could answer. But we’re really, really clear with the children that they
119  can ask anything and we’ll answer anything, obviously within reason.
120
121  _Yes ok. And parents are comfortable with you ...._

122  Carrie > Yes. Parents are happy with the whole process. We seek their permission and they
123  send back consent forms saying that they agree.
124
125  _Ok, lovely. I was going to ask how confident you feel delivering this curriculum but it seems
126  like you are quite confident and the TA is also quite confident..._

127  Carrie > Yeah . You know the last one I delivered was on a 1:1 with a girl but that was
128  because she was in year 9 and she was becoming quite promiscuous. She became aware
129  that she was quite attractive to boys and not knowing when not to be flirtatious. Also, we
130  did a lot on social media because she was making friends with boys in different countries. I
131  mean I say ‘boys’ but we don’t know if they were. And it was trying to explain that and get
132  that through to her. However, she was not autistic but had very profound learning
133  difficulties.
134
135  _Ok_
Carrie > But social media is a biggy as well. We did talk about that. I don’t know if the TA is doing that this time around but we have done it in the past.

That’s another important topic.

Carrie > Uh huh

Ok as we’re on the topic of ‘topics’, so far you’ve mentioned consent, legal age, contraception, when to stop and when to say no, different kinds of relationships and social media. When you say different kinds of relationships, what in particular are you referring to…?

Carrie > So we’ve looked at, like I was saying, sort of nucleus of your family and then friendships, and then any form of relationship you might want to have. Something else we’ve done actually, we’ve watched clips, appropriate clips from First dates, when men have got it wrong, women have got it wrong and what mistakes they’ve made. So we’ve used …I think the difference as well is explaining to children with autism, what’s a friendship, what’s a relationship with a family member, what’s a sexual relationship and a relationship with a partner. They’re three very different things that get very blurred for autistics. So almost breaking it down into 3 separate columns – this is what I do with my family, this is what I say to my family, this is what I can do and say to friends, this is what I can do. And when is it appropriate for a relationship with a partner to become sexual.

Hmm…ok. Are there any other topics you think that might be important to include in a programme of RSE?

Carrie > Yeah definitely consent. I know I’ve spoken about that but for the girl I was working with that was a biggy, knowing what is acceptable and what isn’t. So we talked about everything. Absolutely everything to do with sex and what is acceptable, when it’s ok to do things, when do you stop if you feel forced into doing things, what part of the body is ok to be touched at what stage. Uhm… so that, contraception is a huge one, huge because a lot of our children they learn about sex, they learn about relationships, putting it into practice is, then can cause all sorts of chaos if they’re not using contraception.

Uhmmm.. definitely. Are you aware that from next year this area of the curriculum is going to become compulsory?

Carrie > Yeah

Do you see that as offering any change to the way in which you do things now or...

Carrie > In an ideal world I’d like to think that all of the children with lower ability and special needs were taught in a slightly different manner. Uhm… unfortunately it’s not going to happen because of resources so we’ll continue working with children with autism and the children who are lower ability, with an EHCP probably that need it more explicitly delivering.
Ok just a final question...this one might be a bit tricky. I know you said you got support from the autism outreach team in the pst, but do you see any role at all for your EP ....in supporting...

Carrie > Oh yeah...if that was a possibility, I mean for us it’s always only ever going to come down to cost unfortunately. If it was a service that was provided FREE, that would be phenomenal. I know it’s never going to happen, but it would be lovely to get a perspective from a psychologist, definitely.

Do you mean like in the reports...?

Carrie > uhm... no, more in the delivery of the group, or popping in maybe once every couple of months to see what we’re doing and maybe... steer things in a direction they feel would be appropriate. I mean I think we do it well but it’s always lovely to hear it from somebody else’s perspective, whether that’s a psychologist or autism outreach both of which are just as valuable really.

Ok Carrie, thank you very much for talking with me today.
Interview with SENCo 2 - Roy

So Roy, I have a few questions but we may not stick to the script, we’ll see how it goes. Let’s start first of all with your understanding of the term Relationship and Sex Education

Roy > My understanding of the term of Relationship and Sex Education….So I suppose it’s educating young people about some of the uhm uhm challenges and dangers and social conventions and hopefully also pleasures of uh…relationships and … including physical relationships and all aspects of sexual behaviour.

Ok. That’s a full comprehensive answer, that’s fine. Do you see a need, with specific regards to young people with autism, do you see a particular need to deliver this curriculum?

Roy > Do you mean do I see a need to deliver the curriculum in a way that is differentiated from what you would present to uh… a group of neuro-typical….

Yes

Roy > Young people?

Yes… to deliver it in a different way then...

Roy > With some people with autism, yes… depending on their level of understanding around the uhm… societal norms and conventions. With some, yes, with others, no.

Ok

Roy > I suppose it all depends on how well this has been handled in the family or to what extent the… young person takes notice of what the family say. I mean, we have one very highly sexualised young man in Year 10. He takes no notice whatsoever of what his mother tells him about matters to do with sex or… nudity in the home or sexualised behaviour in the home, but if I tell him, he listens. ...

Ok

Roy > Because I’m a teacher

Right

Roy > So if I say don’t walk into the bathroom in the state of undress when your mother is in there, he takes that on board. When his mother tells him not to, he ignores it. So it depends…. I think it depends very much on the needs of the individuals or the cohort of autistic students you have got.

Ok. So you are in a mainstream setting here. Uhm… would you deliver this curriculum like you said depending on the cohort of pupils, will you decide ‘Ok I’m going to take this
particular group out and do something with them while others can stay in the mainstream class?

Roy > What we’ve usually done is uhm... in most cases, in addition to what they’ve done in the mainstream sex and relationship education lessons, and this is one of those things I’m saying that actually as a school, we’ve not been as good as since the schools merged, and I’d like to get back to it. It used to be a personal development lesson once a week which was a really convenient time to take any students out of anything for interventions. Sex and relationship education was delivered as part of that. But what we sometimes do is withdraw a group at another time to give sex and relationship education sort of as a... in addition to what they have done in a mainstream group with a focus specifically on what young people with autism might find challenging. There are some of our students we knew who would never cope with... being in a mainstream sex education lesson, so we deliver it to them separately so again, I think it really, it really has to be based on individual needs rather than a blanket approach.

Yeah, so the ones who wouldn’t cope at all, they wouldn’t have that opportunity to have it with everyone else? You would just take them out?

Roy > They would have it in a smaller group of children with similar needs.

Ok, alright. Uhm....well that kind of answered my other question which was uhm... do you see a need for it to be tailored to suit the needs of specific young people?

Roy > Oh massively yes! Massively! So the young man that I told you about, well luckily, I’ve got a good relationship with mum, who will describe sort of inappropriate sexual behaviours at home. Well then you can tailor the lessons to make sure you are covering, you know, who is acceptable to be naked around, and when, and where and that sort of thing. We had another young man who, uhm... had uhm... had himself....had inappropriate sexual contact with a younger family member, so that had to be addressed in those lessons, you know, it is essential in order to help to stop that kind of behaviour.

Yeah, in cases like those, would you do it one to one with that particular....

Roy > Yeah I have done in those trickier cases. In other cases, it would normally be with a group of about ...I don’t know... 5,6,7.. uhm... unfortunately, my colleague who is an HLTA who has also delivered this curriculum, couldn’t be with us today, she doesn’t work on a Friday, but the way we used to do it was I take the boys group and she takes the girls group.

Ok. You’ve found that’s worked well?

Roy > Yes

Ok, Before you delivered the curriculum, was there uhm...would you have shared that with parents....

Roy > Oh gosh yes!
Exactly what you were going to deliver?...

Roy > Only uhm…. No, not quite to that level of uhm… specificity. We would always get parental consent for any intervention we run that involves withdrawing someone from a lesson.

Ok

Roy > So I would generally ring up the parents, give them a bit of a gist about, you know, ‘We’ll be covering this kind of thing’ and they would say “oh yes please”, usually.

So that’s verbal consent not necessarily written...

Roy > My way was to get verbal consent. My colleague who is now the SENCo of the combined schools always seeks written consent for any intervention. So I think so long as consent is given….

It doesn’t really matter how...

Roy > To me it doesn’t (laughs)

Yeah, you said you wouldn’t share he curriculum per se, you’d just say we’re covering x/y topic and that’ll be it?

Roy > Yeah. Well I suppose they never asked for anything more specific than that.

Ok alright, lovely. So at the moment, how do you deliver ASD to pupils? You mentioned in the past when you were on 2 sites….how do you deliver it?

Roy > At the moment, we don’t and I’ve not figured out how we’re going to do it. Uhm… since the schools merged it’s trickier for a number of complicated reasons to uh… withdraw students from mainstream lessons. There isn’t that personal development lesson at the same time every week where you can kind of conveniently go out for the next rotation of personal development – ‘I’m going to take so and so and so out’. I don’t have as much non-teaching time on my timetable. I haven’t figured out how to do it yet. I’m hoping to later in the year.

Ok. I hope that works out….

Roy > I do...(laughing)

But do you think definitely there is a need to deliver it…. in a separate way or...

Roy > I think we have some students for whom there’s a ….. Yeah, I think for some students for whom there is a need or at least it would be in their best interest to have something like that.
But the vast majority, for the time being, do it in mainstream lessons?

Roy > For the vast majority that works well and you know, we have a large number of young people with autism at this school, actually most of them have very high functioning autism and it’s not a problem for them to attend the mainstream lessons.

Yeah, ok.

Roy > And I’d like to think that our teachers are well trained enough in autism that they could take that into account.

Alright. When, when you did do it, uhm…was there a specific programme that you followed?

Roy > I don’t really like following a specific programme myself. English is the subject that I teach and I think English teachers don’t like following a text book so I had a couple of different curriculums that I could mix and match from. One was from Nottingham City, uhm… and the other one was the Scottish National Autism uh….SRE curriculum. That one was really good I thought. Yeah, I would sort of take bits out of both of them and sometimes make up things of my own.

Ok

Roy > Depending on the individual need.

Ok, so the programme was just a guide?

Roy > Yeah

And you tailored it to suit?

Roy > That’s right, yes.

Ok. How confident do you feel delivering that curriculum?

Roy > At this point, very. The first time I did it, it was uh…it was uh… my line manager said ‘Look this really needs doing’, uhm….when I, when I was sort of new to becoming specialised in SEN and I’d never done any, I’d never taught any sex and relationship before. And you think ‘Oh gosh, what silly questions are they going to ask?’ and that kind of thing. But uhm….you know, nothing, nothing shocks me now.

And how long have you been doing it if you don’t mind me asking?

Roy > Oh, it must be 6/7 years, 7 or 8 years maybe.

So you are very experienced?
Roy > Yeah and I learned very quickly that actually, when you are delivering a curriculum like that with young people with autism, they would say and ask things that a neuro-typical young person would be too inhibited to.

Yes, yes

Roy > So it is very eye opening.

Yeah, and you are very much prepared for anything that comes your way, pretty much...?

Roy > Yes

What about the other member of staff who does it? The HLTA?

Roy > She’s confident in all situations. I think, I think she finds it unflappable and uhm...she had one young lady who really did not want to take part a couple of years ago and, ‘No this is important, you need to know this. This is going to come up and this is what we’re doing’.

Ok

Roy > The only times it’s been really tricky for me is...there uhm... we had 2 brothers who were from a very religious family and uhm.... I think they used their religious beliefs almost as an excuse not to. They were the kind of boys who wouldn’t have wanted to take part and so they were like... ‘this line drawing that you have given me is filth, it’s pornography, our priest would never allow us to look at something like this’. That was tricky to handle.

And how did you go about handling it?

Roy > Not very successfully. Uhm.... I think in one case, we... I think the older brother eventually sort of relented and you know...this is....’you might not be interested in this, you might not uhm...want to know this but you are going to have these physical urges and you need to know this’. And he sort of...from a scientific point of view.... Kind of went ok. The younger brother I think in the end, we abandoned because he just would not... he would sit in the corner and sulk.

Ok, alright, that’s unfortunate. Uhm...moving on to the other question, what kinds of topics do you see as being important to cover. I mean, there are the obvious ones, but.....

Roy > With autism for me, just looking at the needs of our students, its uh...with relationships it’s kind of understanding what makes somebody a boyfriend /girlfriend or a romantic partner because often they misunderstand....maybe misunderstanding is not the right word. You know a lot of young people with autism would consider as a friend somebody that you and I would consider as a casual acquaintance or, or sometimes even less than a casual acquaintance. So it’s making sure that they understand if somebody is your girlfriend, these are the things you would do, and this is how often you would see that person and this is what that would mean and if it’s not at that level then most people wouldn’t consider that to be that and it uhm... so there’s that side of things from a relationship point of view and
then from a physical point of view its often things about...when it’s acceptable to expose yourself or who can you be naked around...or...where and when can you be naked or....where and when is it appropriate to masturbate and things like that that I think neuro-
typical young people intuitively pick up on ..... 

But the autistic child wouldn’t...

Roy > One young man whose mother was tired of him going around the house in a state of undress and all this kind of thing. So she had a conversation with him about masturbation – you do it in your bedroom, you close the door and you wash your hands afterwards. All those kinds of things that actually I would have taught in lessons anyway, except then he was then saying ‘I’m going up to my room for some private time. Nobody knock on the door!’ And then emerging shortly thereafter with a tent in his trousers and a red face, and so we’d have to cover things like that as well (laughing)

Yeah, I imagine you would have to cover things like that as well. The groups I spoke to mention that in these times, things like gender awareness and gender identity...

Roy > hmmm

Is that something you feel is coming up more and more

Roy > Do you know what? Actually I suppose it is and it’s not something that I’d built into the curriculum last time I delivered it but I suppose it’s the kind of thing that they might ask about. Yeah. I hadn’t thought of it. Yeah had it come up, but I don’t think it had.

Ok. And one of the pupils I spoke to as well said that what wasn’t included in their curriculum was things like LGBT and that kind of thing ....

Roy > hmmm Oh yeah I did cover that and in one case it was very much at the student’s request. But I would have anyway, about uh...and I think some of them were curious about how gay people have sexual intercourse and what would be the differences between gay experiences and heterosexual experiences. Yeah and I think it’s one of those things even if they don’t want to know, I think it’s important that they do....

That they know....yeah, definitely. Ok. I don’t know if you’re aware but from next year there are going to be some changes to the curriculum in terms of sex ed. It’s going to be called Relationship and Sex Education and there’ll be a focus on relationships at Primary school

Roy > Is this part of the National Curriculum?

Yes

Roy > Oh I wasn’t aware.
Yes and at secondary school, that’s where you’d be bringing in more the sex education. The emphasis really is on relationships which is why they have put that first and it’s going to be mandatory. All schools will have to deliver to all their pupils.

Roy > Well that’s good

How do you see that affecting what you do here with your pupils with autism?

Roy > Well, I’m not involved in the mainstream relationship and sex curriculum and I don’t deliver it so...that will be the only reason I was unaware. Like I said, we’ve let things fall by the wayside a bit since the schools merged because there are so many challenges around that. I’d like to deliver the curriculum again so I’d want to make sure in light of what you’ve just told me that I’ve met with members of staff who are responsible for the delivery of the mainstream element so I could make sure that I was covering this...the same topics, or maybe not covering the same topics, that I was complementing it, you know...

Yeah ok. I think we’ve touched on most of what I have here. I don’t know if there’s anything else you want to add that I might not have brought up in terms of the topic, any issues that may have come up in the past.....

Roy > I felt like there was something a minute ago but I can’t remember it ...I’m a bit foggy headed today. Uhm...oh I know what it was, it was pornography.

Hmmm

Roy > And of course, you know, teenagers, teenage boys these days have access to a wealth of pornography at their fingertips so I ....

So you’re thinking that as a topic to include...

Roy > Well it’s something that I have included and I’ve found in my teaching that there is a wide range of experiences that some of the students had had, where some even in year 8, year 9 had been viewing a lot of internet pornography and just considered it as part of their...their entertainment almost, part of their sexual lives. And they couldn’t understand the reason really I was telling them why somebody their age really shouldn’t be and why 18 was considered the age... And others who were sort of horrified by the idea of it and wanted nothing to do with it and it never would have occurred to them.

Yeah

Roy > But it’s important to be included isn’t it? I think teachers are embarrassed to talk about it sometimes but our young people...

Are accessing it...

Roy > Are accessing it, yes.
That’s interesting because when I met with the pupil group and I asked you know, ‘do you turn to the internet to find out information or anything like that?’ They all said ‘oh no’ so I don’t know. Maybe I was with a group that didn’t...

Roy > Or they didn’t want to tell you. I don’t know but there is such a range of...I don’t know, the kind of level of sexual interest among autistic young people and so some are...if you had a group of as I say it’s often year 8/9 so if you had a group of 13 year old autistic boys infront of you....hmmm...ok some of them are going to be...to have the sexual proclivities of a typical 14 year old boy which is to say, they are going to be very interested and for some...it just would never have occurred to them. You know I’ve found...I find a lot of them don’t really understand...even if they understand at an intellectual level about growing up, they don’t understand that part of growing up is that your interests and your tastes change and mature. So yeah, it varies enormously. I suspect some of them had though, don’t you?

Yeah, of course I did. One said just to get info for homework...

Roy > Well that’s the real danger isn’t it. That actually some of them will look at pornographic films online and think that this is a realistic portrayal of what to expect from sex and it’ll be sort of information gathering and that’s worrying.

Yes it is. Ok Roy. I think that’s it. Thank you very much for your time and for participating in my research.

Roy > My pleasure. Glad we could meet finally.
TA Interview - Alice

So Alice, can you tell me what do you understand by the term ‘relationship and Sex Education’?

Alice > Uhm I understand that relationship and sex education, well not just particular. It could be anything with anybody so everyone has a relationship. It could be with a parent, with their friends. It doesn’t have to be intimate. There’s even relationships you have with games and thing that you use because there is a relationship... an understanding, do you even understand how the game works and how you interact with each other. Uhm... sex is more the intimate part of a relationship...

Hmmm... a very comprehensive answer.... Well done. Uhm, with regards specifically to young people with a diagnosis of autism, do you see a need for this to be taught at high school?

Alice > Absolutely! The small group that I take, that I teach sex and relationship to, they have a very varied knowledge of the subject. So some of the children understand what a relationship is and other children only see it as a ‘boyfriend/girlfriend’ thing. They don’t understand, uhm... how wide, how much wider it could be. So even though some of the children without diagnosis would understand the concept of a relationship, they (children with diagnosis) don’t seem to be able to grasp that quite so easily.

Ok... so definitely a need to be taught.

Alice > uh, huh

Do you think the curriculum needs to be tailored in a particular way for young people with ASD?

Alice > Absolutely. A lot of children will be able to read between the lines and will be able to pick up on certain nuances whereas children with ASD, they won’t be able to do that. They do need it pointing out, bit by bit right down to the finest detail or else they just won’t understand it.

Ok. Do you currently teach pupils with ASD RSE?

Alice > I do. I have a small group of 4 boys that I just responsibly go over the relationship and sex education curriculum with bit by bit. At the moment we’ve got as far as: What a relationship is and about personal spaces, about uhm... consent, and we’ve just touched on anatomy. So even though they have done that before in Science, they have forgotten the majority of it, we’ve had to go back over it again.

Ok. Is that because they just didn’t understand or there were things they wanted to explore further...?

Alice > A mixture.
Ok

Alice > They’re very much a mixed group as well, the abilities and what they remember is mixed.

Alright. So you’ll say for the most part they’re enjoying these sessions

Alice > Yeah I think so, the majority. We start off with rules for the group pointing out that everyone has a right to be heard and have an opinion, that it is not discussed outside of this room...and then we’d go on to...I’d do a little ...I’d do my opener and then we’d talk about any questions that we wanted to. And because they know each other quite well, they do ask, ask questions. Some of them will know the answer and they’ll laugh, and others won’t and they’re a bit more serious. But on the whole, they do enjoy the sessions.

Ok. You mentioned there that they understand that what’s taught shouldn’t be mentioned outside the room. In terms of parents, are they allowed to go home and...

Alice > Oh absolutely. It’s just in the case of... if somebody says something regarding themselves, that isn’t discussed, that’s personal information so they can’t do that. But uhm..yeah. We have permission slips from parents so they know what is being discussed in these sessions and I do say go home, especially when they start discussing and asking questions from a male perspective, I can’t personally answer, I’m not male, so I say go and ask dad or older brothers.

That’s good. I asked that because when I met with my parent group they voiced concerns about things being taught at school and then the children coming home and discussing things and they were like unaware that that was taking place. So it is good to know that parents are made aware before you start and it’s that open dialogue between school and home. Ok, you said that you teach a small group of about 4

Alice > Yes, 4 boys

Are there opportunities for 1:1 sessions? So if there’s one in the group who hasn’t quite got something, would there be an opportunity to ....

Alice > Yes there is. So there was 1 boy who missed a session of anatomy, the male anatomy and so I have got an opportunity to go through it with him separately at a later time. So I do a separate group with him that I could pull him out of and quickly go over with him so he’s not left behind and could catch up.

Ok. And Alice you’re a TA, how confident do you feel delivering this curriculum?

Alice > Uhm...I feel fairly confident but I think that’s more down to the fact that I’ve supported these boys for quite some time and we know each other quite well. So I know their reactions and they feel comfortable enough to talk to me about it. So had it been with anybody else that I wasn’t quite, I didn’t know quite so well, it might be different.
Ok, so you think it’s really important that whoever’s delivering this, has a relationship, a working relationship with the pupils and know them quite well.

Alice > I think so, especially with autistic children because they don’t like change anyway. If it’s somebody new talking about something they find embarrassing, that would be even harder for them to take in. They’d perhaps be sitting there thinking: ‘I want to get out this room, I don’t like this’, rather than actually listening to what’s been said.

Ok, lovely. Uhm… were you aware that, I think I may have mentioned this before, or I might not have, this curriculum becomes compulsory next year…

Alice > Yes I think you mentioned it earlier.

So how do you feel about this? Do you think that’s going to change anything for you in any way or…

Alice > (Laughing) I might get more groups next year. Apart from that, not for me, it won’t change anything. I think it’s a really good idea.

Why?

Alice > I think they need it. I think when they get older and they go out, they could be really vulnerable.

Ok. Let’s talk about the topics. What topics do you see as being important to cover?

Alice > You mean I’m doing at the moment?

Yeah, or any others you might think important that might not be on there. So at the moment you’re using a programme by Fiona Spears?

Alice > Yep. It covers everything about relationships, what a relationship is, different kinds of relationships, good relationships/bad relationships and what they are. So about being a friend, what makes you a good friend, what makes you a bad friend, things you could do and it goes on to intimate relationships. So if you like somebody, how do you know you like that person? Do you get any different kind of feelings? Or if somebody likes you, how do you know they like you? Is there anything they’re doing or saying that makes you think they like you more than just a friend? So little things that these children don’t normally pick up on at all. I then go on, I’ve done so far, I’ve gone on to anatomy and what, the female anatomy and the male anatomy and just the basics of what it is, where it is and I’ve not yet done about intercourse or sexual relationships…

Ok, those are all the usual things you’d expect to be in a programme such as this…

Alice > Uh huh, we’ve done about puberty and about changes in the body, uhm….right down to the fact that they need to wash more often because you could smell. I’ve done about personal space and it was quite interesting to find that some of the children had a very wide
personal space and there was another child that had none whatsoever. He was very comfortable with anyone standing as close as they liked. So that was quite interesting.

_Hmmm... just goes to point out the differences in all of us...._

Alice > Yeah

Ok. So when I spoke to the SENCo earlier she mentioned things like consent, legal age contraception, when to stop or say you’re not happy with something, social media, uhm...anything else you want to add to that list in terms of ....

Alice > No, we’ve touched on social media and I’m going to come back to that separately. It was quite a big issue. And gaming and how to keep yourself safe online. That’s another thing because they do do a lot of gaming where they chat to people and they believe whoever they’re chatting to. They don’t understand that that person says that’s who they are, and put a picture up of who they are but that actually, that could be anybody and they don’t quite get that, that someone could be that deceptive.

_Hmmm...ok. Fantastic. So I think Alice, I’ve covered all my questions no, so thank you very much for your time. If there’s anything you’d like to add?_

Alice > No. I’m fine

Ok then thank you.
Appendix 17

AOS Transcript
AOS transcript

Question 1: What is RSE?

Ok, so I’m here with the Autism Outreach team and we’re about to start our Focus Group Session and I’ve got 7 people present. The first question that I’m going to throw out to the team is: What is your understanding of the term Relationship and Sex Education (RSE)?

Jill > Relationships are to do with family and from family in the wider community. So that’s in terms of Relationships.

Andrew > I’d like to go further and say relationships is also about how individuals relate to each other in terms of, which may over time produce a relationship from the point of view of a family or friends perspective.

Oh alright. Anybody else would like to share their understanding of RSE?

Jill > Since we’re thinking about autism, sex education might start with the individual understanding for themselves, their sexuality, their... practical things like body changes, as well as the relationship side of sex education and what that means both from a practical point of view, but also from a sought of emotional point of view as well.

Andrew> I’d also say that around sex education we’d also be from and autism perspective, wanting to understand the point of view of consent, and the theory of mind from another person’s perspective. And, and, and how therefore, uhmm, that impacts.

Jill > I think in schools as well, sex education is a good opportunity for cross curricular links so between Science, PSHE, SEAL, there are areas to work together, to have really clear outcomes.

Question 2: A need to teach RSE

Ok. So it seems like we have quite a broad understanding of the term as I would have expected. Uhm, so we have the relationship side of things and we also have the sexual aspect and preparing children with ASD for that and in terms of giving consent and what not as Andrew mentioned. Do you see a need for young people in schools to be taught a curriculum of RSE?

Andrew > Well particularly children with autism, or just autism?

Particularly those with autism. Yes, sorry.

Andrew > I think it should be looked at as very individual and I think that just because data has shown that certain people may engage at certain ages in sexual relationships, doesn’t mean that all should be.

Ok, that’s a fair point. Anybody else?
Andrew > people with autism, uhm, if they’ve got a diagnosis of autism, you therefore see as part of the diagnosis, they have a social communication difficulty and therefore would uh, present as more likely to have difficulties in understanding about relationships and sexual sex education. So, uhm, therefore, from that point of view, to answer your question, I feel that there should be. Not necessarily, it’s how it’s delivered is an important factor, but there should be consideration that young people with autism are less likely to pick up the subtleties that are sometimes taught in the normal approach to teaching sex education and it’s not explicitly taught from the point of view of understanding from another’s person’s perspective.

Ok so I’m getting that you think it should be taught but that it should be delivered in a way that’s sensitive to the needs of each particular child, not even just all ASD pupils as a whole.

Bob > Yes. If I can just… Because obviously the diagnosis of autism and the difference in processing information that obviously that could lead to…is…explaining to a pupil with autism that their relationship with another person might be different from the norm as well. And that’s ok. Just thinking of recent TV programmes that have been on around Chris Packer and his relationship with his girlfriend is very different to a neurotypical relationship. And highlighting that actually, a relationship with another person doesn’t have to fit a particular mould that society has created. I think, a relationship with another person is a very individual thing because I know just within this group here that relationships between partners, husbands, wives, boyfriends, girlfriends, it works for those two individuals. And for the person with autism to be told that that is ok even though that’s different from maybe the majority of relationships that they’re seeing in their peer group is really important. And not to feel almost…I dunno, a stigma attached it just because their relationship is different. Because I know my relationship with certain people is different to that of others.

Lisa> Uhm… just to say as well that if you’re looking at the curriculum of RSE for young people particularly with autism, then involving parents in that and making sure that they are exactly familiar with what’s being taught so that they can reinforce messages at home. And also address any misconceptions that arise because I’m thinking of an incident where a parent, where her child had sort of access some RSE at school and her understanding was that the age of consent was 16, so at 16 she had to go and find a boyfriend because she had misinterpreted what had been delivered as a key message. So, uhm, for that parent she had to sort of have another conversation where they explored that a little bit differently with that young person.

Rebecca > I think that education needs to think about what children can access outside of school and also, for youtube for example and various other websites and they need to be quite explicit on whether it’s ok to be looking at those types of websites because some are harmless so to speak but might not be to all children.

Question 3: What topics to teach?

Ok. So you’ve covered quite a range of things there which uhm, may have been part of my other question which is what kinds of topics should be included in a curriculum of RSE for someone with ASD? So you’ve already mentioned social media, you mentioned age of
consent and emphasising that even though that’s the age, it doesn’t mean that you have to start doing stuff at that age. Can you think of anything else? Anybody feels anything else should be included on a curriculum?

Ruth > Yeah I think, you (referring to Rebecca) sort of hinted at it, but what they are accessing online. So pornography is making it more and more on to schools curriculum around sex education and actually addressing, what... you know, in a more transparent way what you’re likely to see, how you need to weigh that up versus reality. Uhm... some of actually the risk around porn addiction, some of the physical results of that and I think, particularly for children with ASD, just in a really clear kind of relaxed way. Kind of putting some of that across so again they don’t go away and think well, everybody else is looking at porn, I must be abnormal if I don’t want to, if I don’t have those kinds of discussions.

Maxine > I think some issues just sort of cover the whole range of sort of young people not just uhm, individuals with autism. But I think just the concept of peer pressure and peer expectations. So whether it comes from what some people have seen on Youtube because young people will have different access at home depending on, sort of parental regulations and so on. Uhm, but just of giving young people a chance to be aware that, of the difference between what is a ‘people say’ and what actually happens and, and how to manage peer pressure. Because I think that’s particular for teenagers and I’m not sure if that’s the range we’re looking at. But that’s a big component in young people’s behaviour.

Jill > Again, like Maxine said, this isn’t necessarily ASD specific but the fact that a lot of people with autism are at a higher risk of Stress and anxiety, I think it would be really useful as well as part of SRE to include the relationship they have with themselves as well.

Andrew > Uhm, the other factor as well in terms of young people with ASD are more likely to have SPDs, uh, sensory processing difficulties and so consideration needs to be taken into when discussing. These are factors that the mainstream RSE curriculum just would not take into consideration, how the sensory idea impacts as well. Are you talking just about mainstream?

Specifically, yes.

Andrew > You are? Alright. So we won’t talk about learning difficulties.

Lisa > Yeah uhm...so following on from what Andrew said, so thinking about some things that are typical for, in terms of the thinking style of a young person with autism is change and coping with accepting changes within one’s own body. So I’ve experienced young people that have been very resistant to the fact that their body is going through physical changes. So that is, so I think, looking at that as a particular issue is helpful as well as really practical strategies around how to manage certain things whether you’re male or female. And being really concrete and explicit. And I think maybe in sex education things can be very explicit but we still make a lot of assumptions about, you know, where it’s safe to, how we can do things, who it’s safe to ask. So whether it’s around masturbation, whether it’s around periods, but it’s just being really explicit and therefore what’s within the comfort level of that young person. An open forum may not be the best place to discuss it with peers and
it’s, it’s just making, as we started out saying, what is right for that young person to make it bespoke.

Question 4: How to teach?

So I’m understanding that ideally you think it should be delivered in a 1:1 context if possible, or as far as possible?

Andrew > based on needs, attainment

So it depends on the needs of the young people, you may be able to group particular ones?

Andrew > I don’t think one could make the assumption... that generically.....It’s got to be looked at as... can that individual...I don’t, I don’t think you could generically state a statement that people with autism need to be taught in a 1:1 capacity. It’s still, as with any education system, the best model would be a bespoke model to the, to fit the needs of that particular individual in that particular context.

Question 5: A role for the AOS

Uhm... do you see a role for you as the autism outreach service in helping to deliver this curriculum in any way or supporting schools in delivering this curriculum?

Jill > I think we already have a role because we respond to the needs that arise and we know that particularly in secondary settings, quite often issues do arise around a young person’s understanding, with autism’s understanding of relationships. The boyfriend, girlfriend concept and what that means; issues where someone may over focus on an individual. There’s a whole range of issues that might come up, so I think in our role, we would definitely see that we would support schools in responding to that. But the question about whether we then directly contribute to the sex education, uhm... relationship and sex education in a school, I think, you know...we... I think... we would certainly, where we know a young person has got, or is likely to have those kinds of issues, offer to sort of discuss with the school or with the key person how they might sort of look at embedding certain things within the curriculum but without it being our responsibility to perhaps deliver that because that’s too specific.

Andrew > Effectively we are the autism translators, aren’t we? So we, we are in a position where, where we’re, we’re helping to take information and put that across to staff to empower them to be able to deliver this, the message that they’re wanting to deliver but in an autism friendly way. Uhm, we’re, we’ll also probably be more concentrating on accessing research, resources and information that shows best practices and being able to invest ways of doing that whether that’s collectively in putting together a workshop for those people delivering it, but I think that best practice in terms of delivery of RSE would be delivered from someone that knows those young people themselves and perhaps have some sort of relationship, uhm, professional relationship with them already, uhm, so that there’s that feeling of comfort as opposed to just someone coming in and delivering it.
Bob > And I think what you said about that workshop or working alongside staff delivering that, we would be there to offer pointers for that more specific, bespoke teaching as I think Lisa alluded to earlier, about how to deal with... a break up, or how to let somebody know that you’re interested in them in maybe a romantic way, without going too far and becoming overly interested and almost obsessive.

Bob > Yes, that’s right... And what are the differences and what those good, you know non-verbal, so your body language, you know, *how* you would come across and show somebody that you like them in that way. I think that’s something, something we would discuss with, you know, staff actually delivering the general programme which is a lot of what we do.

Ruth > Yeah so, because uh... As a team... we...we’ve got some resources or strategies that we would recommend for your young people with autism, those are the same strategies around this. So, is a social story appropriate? Is it about a 1 to 5 scale in terms of physical behaviour? Is it that uhm... you know... ahhh... socks... I can’t remember the abbreviation ... situation... yeah so it’s using those tools that we already know well. They’re more visual, they’re more concrete and then adapting those to this issue. Because some people panic, both schools and parents because of the nature of it. So we just want to ground that with, using what we know.

**Question 6: What do we teach? Is there a programme to follow?**

*I’m glad you brought that up Ruth, because I was going to ask next: If there is a school who had a child that required special intervention for RSE and they came to you said, ‘Well we don’t know what to teach?’ Is there a programme that you use currently, that you can share with the school? Or is it just a bit ad hoc?*

Andrew > There are so many materials. So we can look at Fiona Spears’ materials. Uh... Lynn Moxon’s materials from ESPA, uhm and there’s whole programmes there that perhaps have not been constructed by ourselves. Um Isabella Hanou’s work uhm, it’s all published through Jessica Kingsley. There are books, materials, I think again, it’s like I said earlier on, is that, we can present that, any information, the material is put in an autism friendly way, being able to understand the basic understanding of autism. Actually we were talking about continuing to alluding to the non-verbal cueing and issues etc. And I think that’s what we would do. To pick up a programme creates a danger *cos: ‘Well here’s a programme, we’ll fit the child around the programme’ whereas I’ve always been where we fit the programme around the particular individual. So I’m quite averse about just picking up a programme without...we... we’d send that message to a school where, well it says here’s a programme about autism, here’s a child with autism so therefore... I’d prefer, I’d much prefer to take Fiona Spears’ work, for example which has got some pointers, some ideas and... and... and then moulding it that way.

Ok
Lisa > And then we did uhm... deliver a sort of uhm... a training presentation to parents and schools last year on uh... uhm... sort of adolescence and looking at adolescence and where that fits in with autism. And ... and then looking at some of the strategies with case studies of how they were used and the outcomes. So that does kind of exist but then as a general tool.

Ok. Thank you. And I think my last question because of time. Uhm.. I just wondered if you were aware that are changes to the curriculum coming into force next year that’s going to make RSE mandatory and how you feel...whether you feel that’s going to have an impact on your work or not? Would things change? Would thing remain the same?

Ruth > Would that be with no exception for religious or ....?

No exceptions but I think there was a clause where, in religious schools, parents would have to write a letter to withdraw pupils. Yeah. But at the moment it’s going to be pretty much... mandatory.

Andrew > I think naturally schools are going to be wanting to look for more strategies and more ideas. Schools will often want to come to the... to get the quick fix – Have you got a programme? Have you got something we could just take off the shelf and use? It might be that we need to be able to look at that and being able to create something as the twilight sessions out there. Uhm... I know, uhm... a colleague of mine who was involved in the writing of the PSHE, the new PSHE curriculum from the university, and that’s what, she was trying to allude, that they were trying to make it autism friendly – in the actual materials that are being put together, as well as inclusive as possible. Uh.. but... I still would imagine that uh... I’d go back to the idea though that if schools have got a better understanding of autism in the first place, they can adapt those materials that they need to be able to deliver it without us having to.

Rebecca > I think the danger is... with it becoming something that schools take full responsibility for, and legally it has to be delivered to every child, is that you, you.. perhaps do lose an element of working with parents on how they support their children in learning about sex education and I think that’s vital because we want that to be happening, you know, to be reinforced and embedded at home. And actually it’s ok for parents to have some choice and some... well that’s my personal beef around how values are taught and how... the importance of different things in terms of relationships and sex ed so you want to retain that parent partnership as much as you can I think and even more so with children with autism so you know you’re on the same page and you’re putting across the same messages. Well that might just be my view.

Lisa > Again just sort of thinking about things we encounter as well. Uhm.. at a meeting yesterday a parent was sort of saying that some of the content of the RSE curriculum that her child had accessed might have been appropriate for him and that was fine. But he then went home and spoke about that with his young sister because he didn’t realise that there was this sort of ... a minimum or maximum age where you should be talking about that. So I think its about explaining to the young people who that would then be appropriate to share it with as well, isn’t it. So I think he definitely not understood that.
Yes. I definitely think there is a role for parents and parents need to be aware of when it’s being... when there are plans to deliver it at school. Get them involved and maybe give them copies of what’s being delivered as well so they’re fully aware of everything. Is there anything else anybody would like to add?

Maxine > I was just thinking about the issue gender identity actually... in terms of... well, 1. The fact that young people are gonna be taught this in a mandatory way and what about considering the gender identity issue, which is huge, and the misconceptions around that and, for someone on the spectrum, the lack of understanding around what that means for them.

So are you saying it’s a topic that could also be added?

Maxine > I think that’s quite huge in fact because I’ve worked with someone who actually experienced that. And this young person uhm... on the autistic spectrum, believed that they needed to change their sex to become female and two years later, it became much more evident that they were actually gay. But they had misunderstood what this actually meant for them and felt that at that time, it needed to be a gender change, and I think that’s huge. So these mandatory lessons that are taking place really need to be, not only mindful about those issues, but they also need to be uhm... educating young people so that they understand what that means.

Rebecca > Yeah. On that as well, what I feel sometimes has been missing from what I’ve experienced, school teachers have said, ‘You don’t just want to be teaching children what is possible, what’s legal. You want to be teaching children what.. to be empowered to make choices that are right for them, are good. Is there any moral framework to it? Is there anything, you know, are we looking at issues around commitment? About what a good relationship looks like, not just what you are allowed to do at these ages or what...what’s expected. Yeah. And I think with the issue of gender identity, culturally you know, what the kind of climate looks like now, actually, we, we need to think about how we’re teaching that to kids. Definitely.

Thank you. So yes, quite a few bits there to consider. Anybody else wants to add anything before we bring it to a close....? Ok, well thank you very, very much for your participation
Appendix 18

EP Transcript
EP group transcript

The first thing I’d like to ask is: ‘What do you as an EP understand by the term Relationship and Sex Education?’

Ray > Well, I’m a former secondary teacher, uhm, and my uhm, I was trained in Citizenship, so part of the curriculum is about relationships and obviously there’s the offshoot into PSHE and about relationships and increasingly about sexualised relationships, uh...including kind of more... recent patterns of behaviour like sexting which has been kind of quite...well researched in the London area. So I think that’s where I’d come from at it. In terms of my experience, it’s about generating positive relationships, helping children to do that, which is a task in itself, and uh... and in addition to that, helping them with kind of, what can be very difficult, kind of, circumstances, uhm...with the use of media and sexting and things like that. That’s kind of where I would approach it from.

Ok, that’s fine. Anybody else?

Tess > I was going to say I think from sort of experience as an early years teacher, as well as looking at things like, not that I taught it, but other friends that have taught it within Year 1, and things like that, you know, to do with anatomy and that kind of thing and naming things and the appropriate labelling of body parts and things like that. And I think that’s where they start it in terms of that, but then also looking at relationships and boundaries of relationships. Like what’s a safe relationship and who do we have relationships with and I guess looking at it from that aspect.

Ok. Fine.

Ben > Yeah. And how abstract relationships are. And because it’s something that can quite naturally fall into... like you say in two ways. You label body parts and things like that in terms of the sex education side. But in terms of relationships, to maybe breaking those breaking quite abstract things down into what tends to naturally occur for a lot of children. Thinking about the generalised population...how...how that happens, and why it happens and how we can make broader relationships and how those different parts of relationships form.

Becca > I think I’d mirror everything that everyone’s already said. Uhm... the only addition would be things around, you know, practical aspects of sex and relationships so things like condom use, and things like sexual health and that sort of thing. I also, I had involvement in delivering PSHE at secondary level with young people who had been excluded from school and because of our sort of... small setting, we were quite aware that there was already some involvement in those kinds of behaviours so it was really, part of our role was around practical resources and that sort of.. delivery of that sort of...information.

Ok, so you said you got involved because you knew the children were already...

Becca > No, so I was, I was a teaching assistant at a setting and then I became an instructor which was basically an unqualified teacher and I was delivering PSHE and uhm... so as part
of that, I was able to respond to needs. Some of that was around relationships. Some of it was around other aspects of uhm... development. But in that particular remit, I thought it was a need that wasn’t met.

Because you were aware that some of the children were...

Becca > Yeah

Already exposed...

Becca > And it was discussed

OK. So...Lexi, do you want to add anything?

Lexi > Uhm... No I suppose I ...when you first kind of said about relationships and sex ed, I was just thinking about a very general stance in terms of thinking about enabling children and young people to develop positive relationships with their peers, with their families as well and also the relationship that they will have with themselves, and how they view themselves, and how that then impacts on their relationships with other people and their interactions and then, you know, how that then feeds in to sexual relationships and what they might look like and ... and those interactions. Uhm... And the different needs (laughs) of children and young people and I suppose what’s expected in terms of ... the subtleties between what kids kind of pick up and what you know... and what’s the differences between what’s taught explicitly and what’s not and what’s uhm... what’s thought of as: ‘Well they should know that’.

Ben > Yeah, yeah

And bridging that gap

Lexi > Yeah. And actually, and also thinking of them in sort of like, emotional development and how that vary and differ and actually at what age and stage they emotionally are. Are they ready to have those conversations and how that changes over time and how it might differ within groups, you know, quite significantly, uhm...

Tess > Actually, I was going to say, yeah, in terms of like... in terms of what changes over time and how like sex education and relationship education has probably changed since we were at school and you know, I , I don’t know in terms of teaching around sexual orientation, uhm... that kind of thing. Like gender, I wonder whether they’re being taught explicitly within school. Is that something that children are kind of aware of or is it something people just think well, they’ll know that because it’s in the media and that kind of thing. But if that’s a newer, another kind of aspect now of, of...that...

That’s a good point. I was going to bring that up a bit later on in another question...so we’ll leave that for now, if you don’t mind. With specific reference to children with autism, with a diagnosis of autism spectrum disorder, do you see a particular need for teaching sex and relationship education?
Lexi > Well, I do in the context of ALL children and young people should be taught about positive relationships and positive sexual relationships and.. and so, for me in that context, that they, that particular group should be included and part of that.

Ok.

Tess > Yeah, Yeah, I agree. I think it’s, you know, it’s part of life and it’s something that they... that every child and young person needs to learn about and I don’t know why you would exclude them from... that population.

Ok. Is that the general feeling for everybody? Do you think it should be delivered then in a different way for this group?

Tess > I think it needs to be thought about in terms of how you would deliver that. In terms of supporting understanding, in terms of what kind of resources you might use to do that. But not being excluded from that... 

Ben > Yeah, so it’s it’s again like differentiating in an appropriate manner so if, if they’re able to access that at the same level as their peers, then you wouldn’t actually just take them out of the classroom and teach them a different approach. If they can access the same curriculum, as Lexi said, I would agree that all children would benefit from that. So if you make a judgement call based on your knowledge of that child on the spectrum, if they can access the same level, at the same pace, at the same uhm... kind of pitch and uhm... with the same resources, then yeah. Why not teach them with their peer group. But you make that judgement call based on your understanding of that child’s ability to cope and access, just like with any other element of the curriculum and school day.

Lexi > Based on their individual needs...

Ben > Yeah, yeah, yeah.

Tess > Yeah, differentiating it. I mean I know when I was an assistant EP we were asked to do the social story for... it was about relationships and safe relationships and so they... like again, not excluding them from that. You’re not saying ‘Oh no you can’t touch... you know, the point you are making in a way is going to hopefully support their understanding of it, so...

Ray > I don’t think targeted support is going to be uhm... as helpful as we’d want it to be if the universal support, you know, the universal PSHE pastoral support at school isn’t efficient. So that’s your starting base, that’s your foundation and then more targeted work uhm... for children and young people with whatever need it might be, in terms of relationships, I think is beneficial under those circumstances. If not I think just totally targeted work if not being universally supported in a nurturing environment, it won’t be as effective, so...
Hmmm. Yeah. Ok. Aright...uhm...do you see a role for the EP in...in ensuring that these children, those with a diagnosis of autism, get this curriculum delivered to them? And if so, what do you think could be our role?

Ben > Yeah so...I would say there’s a role with uhm...in terms of working.... We’re looking really at mainstream settings here, aren’t we?

Yes

Ben > So I would say there’s a role in terms of working with mainstream teaching staff. So this isn’t a ... uh... comprehensive view of mainstream teaching staff, but at times there’s maybe a...I can’t remember exactly who, who it was that said this, it might have been yourself Lexi, but correct me if I’m wrong, but maybe there’s sometimes a view by some staff that, that uhm... they don’t necessarily, they might uhm... they might have an expectation that children will already know this and they might make an assumption that children will already know how relationships work, that they might naturally pick those understandings up and it, may be our role to try to work with teachers to broaden their understanding of: they haven’t necessarily picked those social understandings up although that understanding of relationships and how that works, how to form those relationships and how to maintain those relationships. And I know that’s part of your, the research topic here, but obviously, without that stage of relationships, sex education will probably be undermined or fogged out. We need part A before we get to part B, certainly I would say. So I think it’s that work in terms of broadening what the teacher’s remit is or role in...in...in... certainly in place and then... maybe looking at what tools schools can use to try and build that child’s understanding. So you know I said earlier on about including or ...if...if that child is able to be included in whole class teaching approach, then that’s fine to do so, but if, if that’s not the case, then looking at alternative ways. We, I think we have a remit there. So I know that obviously we’ve got our autism outreach service here but not all services, all local authorities have those services. But also we, there is that crossover at times isn’t it as well for us to provide that input.

Lexi > Yeah I think it is about promoting, there’s an agenda in promoting inclusion, and so all children and young people have the right to be taught about relationships and sex education and so uhm... to...but for that particular group, uhm.... There are some adaptations that need to be made to the curriculum or how its delivered in order for them to have...to be included in part alongside their peers or do they need something more tailored and bespoke and I think, you know, we could have a role in supporting staff at schools and...and also parents in thinking about how those things are taught to their children. And also it might be just about, also be about signposting other services...

That could help...yeah

Lexi > And other places that could support those things as well.

Tess > I was just going to say in relation to parents, I wonder whether there might be a role, I mean I don’t know, but would parents... how do parents feel about their child, you know with ASD, having that education? Is it something that they actually might think, ‘Ooh, I’m...
not sure that’s something I want my child to be part of, to learn about. So I wondered about kind of facilitating and I guess yeah….process facilitating in terms of ... between parents and schools and trying to... sort of engage them...and their understanding of that ...

Yeah

Ray > I think uhm.. a service and local authority can be enhanced with an EP having a kind of specialism effectively, if looking at.. just within the area of autism. I think that generally though it’d be, it’s great for a service to have and educational psychologist with a kind of focus on social relationships and how that ties in with social emotional mental health needs, or communication needs and so on. I think that could really be quite positive, particularly for our increasing kind of post 16 kind of uhm... work. But I think yeah, that would be something that is quite positive but quite specialised as well particularly with a national shortage of EPs at the moment.

Yes. I’m glad you mentioned post 16 because I was going to ask with reference to the ‘Preparing for adulthood’, if you felt there was anything specific we could do with reference to that? Maybe in the recommendations that we write for young people?

Becca > I think that part, maybe part of that is around uhm.... Our awareness and our understanding of maybe specific vulnerabilities that population might have around sex and relationships and using our understanding of what that might look like for an ASD population and then thinking carefully around how we might communicate how to facilitate this in a positive way but also to be aware of ...uhm...any kind of vulnerabilities that may come along with....yeah...having special educational, having additional needs and yeah...

Ben > Yeah. When we think about, say...not necessarily just post 16, but your approaching post 16 community, when we think about girls on the spectrum who may have masked their social communication and interaction difficulties, so at that older age they’re obviously quite a vulnerable group and they may be out, out of their parents’...uh... close control, yeah observation as it were, uhm...they’re obviously going to be exposed to quite a lot of things that they may not fully understand or fully in control at that point. So unless we put this education and broaden understanding at a younger age, if we try to put that education in at that point where maybe they’re feeling out of control, are they going to be receptive to that? So I feel that’s where we need to probably put the education in way, way sooner before we, an again, touching on what Lexi has said, if we pitch that to all, then we don’t need to think about diagnosis first

Tess > I think maybe a secondary age is too ...I think it needs to begin ... you know sort of primary age. But obviously differentiating it so it’s appropriate or at least having those talks about ‘relationships’ and ‘friendships’ and those kinds of aspects of it. More like ‘keeping safe’ and you know ‘what’s a healthy relationship’ and ...‘who are, who shouldn’t, stranger awareness’ and that kind of thing because I imagine, that would be all part of it and correct labelling of body parts and things like that. So if they were vulnerable and in a certain position, then they are able to talk about those aspects of it as well
Ben > And something else that Ray had kind of alluded to, I think with the kind of online, with reference to the online service, something I’ve become more, uhm…not aware of, but familiar with through casework is the vulnerability of youngsters on the spectrum with grooming, with my kind of post 16 population and maybe younger, uhm, because, obviously reading social signs through face to face contact is, can be complex enough for youngsters on the spectrum and if you remove that input in addition, that makes it even more complex for our young people. So that’s an even bigger concern and something again that we need to think about relationships and staying safe.

Lexi > And too going back to your question in terms of what we can do, I wonder whether part of our role is about making those links explicit in terms of… so …in thinking about preparing for adulthood, that actually taking steps in …you know, this could be kind of a collected view that we feel that the education should start you know, from a very young age and obviously be reinforced and changed along…as the child develops. But I think perhaps we need to make those links for all staff and parents…in terms of well actually, we want them to get to, a kind of, hopefully an independent adult and what that looks like and bridging that gap I suppose and being perhaps maybe explicit in our recommendations or our discussions with staff about things …they can be very vulnerable, they can potentially be very vulnerable in like a few years’ time if we don’t so something now to address this aspect …

Tess > And getting them to think about that post 16 aspect rather than saying “well that’s not my problem because that’s…

That’s in the future….

Tess > Yeah, how ever many years in the future…

Ray > Cause it tends to coincide with what parents want for their children. They want them to thrive and have relationships and not to be vulnerable in those. Obviously you can be vulnerable in any relationship and not know who you are, I think that cohort would benefit perhaps from additional support but… uhm…like I say I think universally it’s quite a complex area in terms of, there’s a need there for all children and young people so uhm… so there’s a whole range of approaches required.

Yeah definitely and I think inadvertently, you’ve all kind of answered my other question, which was going to be coming back to what you (Tess) said in the beginning. What kind of topics do you see as being most important to cover? So you (Tess) had mentioned something about gender and those kinds of issues. We’ve also had stuff on social media and….Any other topics anybody thinks should be included…? I think we mentioned consent at some point as well….

Lexi > Yeah I think kind of like practical things as well, you know, like contraception, things like that….

Tess > Like ‘where babies come from?’ Things like that! You know like what happens? How is a baby made? And those kinds of things because you know, I know people who still think...
they come from you know, well they don’t know where they come from. You know those kinds of things...and

Lexi > Like this is what would happen.

Tess > Yeah, you know those practical aspects of staying safe

Ben > And puberty....because that change of....maybe transitioning through that, you know maybe going through that stage where ‘I want my independence’ is probably more complex because there’s that need to....and that depends on mum/dad or carer....

Tess > And I guess self-care in relation to that, isn’t it ?

Ben > Oh yeah yeah. There’s quite a lot of confusion I think at that time. Or can be, so....

All > Yeah

Becca > I think there’s something as well around language and the way that language links to consent. And...I’m talking more specifically about what you mentioned especially with uhm...young women who might by particularly vulnerable to grooming, around the sort of phrases, the sort of language people might use and just...and embedding that more broadly into what consent means and how that relates to your....yeah the consent that you give to being in the relationship you’re in ...

**Having an understanding of the terms used and knowing all the different terminology for particular .....**

Ben > Do you think that enhances their vulnerability online?

Becca > What? The language?

Ben > Hmmm

Becca > I think that for all young women, well for all young people, I say young women because that’s what we’re aware of and that’s what we’re attuned to, but I think that for all young people, consent is a really important uhm...it’s a really important concept when it comes to sex and relationships and I think that a lot of, a lot of what happens around consent is around power, is around control and language is really key in that so I think that, that, again, it’s important for all young people which... I mean universally, are we, are we, are young people having those discussions in school? Who knows, but I think it’s important and needed and that kind of thing should be adapted for the ASD population.

Ray > There was a study, I think it was a programme, I think it’s called ‘Links’. I can’t find it I think it was in connection with some sex ed training that I’ve had where the concept of consent is educated to young people who don’t appreciate the full ramifications and have difficulty with empathising. It wasn’t specifically just for ASD, it was just people in general and you would think...perhaps I was a bit naive in the fact that, I would have thought that
the concept of consent was quite straightforward but that, that programme shows quite categorically that that wasn’t the case and it prevented a lot of reoffending as well through that programme. So ....it was from Southampton. I can find the materials, but it is an important area in general and I’m sure there’s also that kind of cohort for ASD.

Tess > I’m trying to think about some of the strategies that have been used because isn’t there that one where they relate it to like if someone asks you for a cup of tea then you decide you don’t want the tea anymore,

Ben > The cup of tea metaphor.

Tess > I think that, I’m thinking actually, the ASD population might find that very difficult to understand so actually, you know if the school is using that, then actually is that going to be appropriate....

Ben > Yeah

Tess > And some of the ways in which it’s ...Yeah I guess if consent is shown in these animations and things like that, are they things that the ASD population is going to be able to understand. I was thinking in terms of vulnerability as well I guess there’s a need to ...also make children aware of where they can go to if they need support. And that is part of the teaching as well...who can they go to, what agencies are there, what should they do in a situation where they’re feeling vulnerable, what sort of steps they could take. Giving them strategies to manage their own safety as well and empowering them in that way. I think that’s a really important aspect of it.

**That’s a good point...**

Lexi > Also kind of nor....I think kind of normalising that relationships are complicated and that ...whether you’ve got additional needs or not. They can be very confusing and emotional and...and that’s ok but it’s how we manage it...uhm...and what we can do about that and so acknowledging that relationships are hard work ....and we can perhaps all do things in relationships that may not...that we may regret later or...or what have you, and that we need to repair relationships and how do we do that, how do we go about that ....

Ben > Yeah. But what examples would children and young people see which are kind of quite normal. I’m just trying to think.

**Hmmm**

Becca > Well I think that’s the point. The point is that you can’t reference a normal relationship

Ben > Yeah, I know, I’m not I’m not going against what you’re (to Lexi) saying, but I terms of .....  

Becca > Teaching that
Ben > Yeah. Yeah Yeah Yeah. Examples like, For example on television ....

Tess > Managing expectations

Becca > Like soaps...

Ben > And that’s probably becoming increasingly more complex

Becca > That’s a really good point because we had some... we had some input from somebody called...well I can’t remember his name but he has worked at a special school for years and years and years and he was talking about children with special educational needs and how their school approaches sex and relationship education and he was saying that, yeah you have to be really careful about the models that children are using and how lots of children will have these sort of schemas that included like soaps and how soaps have really dramatic, like traumatic relationships in them and that drama is sort of normalised

All > yeah

Ben > I don’t mean like how the make up of that family dynamic but it’s just like... murder, violence....

Ray > yeah, no one goes to the pub any more just for a drink ...

All laugh

Ok so lots of different things there to include in a curriculum for uh ....

Ben > To go back to ....I don’t think we covered too much about ...you know your question about post 16? Uhm... I think one way of addressing that someways is addressing it early with outcomes. So we, I think our role there is about, with our reports and through consultations because if we don’t, if we wait til post 16, I think that’s too late, to some extent. Uhm.. and I think that’s about....I find increasingly, I don’t know why, maybe because schools are having discussions, but increasingly recently, parents seem more prepared to have that discussion with me. I don’t know if that’s just a recent thing for myself, but they seem to be prepared for the short and long term in terms of what they want for their child and particularly for children on the spectrum in terms of what they want and that’s for example things like...To be able to live independently, pay bills, manage themselves in terms of to care for themselves, cook meals...so they are having those thoughts and so then I suppose that not only helps them with what they’re working with their own child with at home, but I suppose then it helps them to maybe....depend on the school but it pushes, pushes back on the school to not necessarily just keep ploughing away with English, Maths, Science, French, Graphics, PE, RE ..... But to develop more holistically...

Ben > Yeah
Tess > I think that’s come… with my EHCPs or casework that I’ve done in primary schools with children with ASD and parents. Yeah, wanting the long term outcomes, and the life skills and the awareness and how to be, stay safe. But also, you know, in terms of their presentation now, describing them as presenting with difficulty in the boundaries of relationships, you know … going to wrap hug strangers and this kind of thing so you know they’re saying this is what they want… they want them to be able to have an independent life and you know integrate but actually they’re highlighting all these things in terms of relationships, in terms of … being vulnerable but you know their wish is that they are safe and highlighting things that are going on now but ….

Clearly its important ….

Tess > Yeah, but I think that’s something, that’s information that always seems to be shared by parents and never something that staff tend to share. Staff never tend to say something like ‘oh we talk about this life skill’. It’s all very academically kind of focused.

Maybe like you guys were saying, it’s up to us (EPs) to try and change staff outlook in some ways and get them to consider this aspect as well…?

Ben > Well I, I’ve been out of the teaching game for a while so I don’t know what, how tight that straight jacket is for teachers to focus on academic …. Well this is becoming compulsory from next year. There’s new legislation, so all children will have to be taught relationship and sex education unless parents explicitly write a letter requesting that they be excused. So staff will have to deliver this and uhm….

Tess > I think it’s about empowering staff as well and also empowering staff not to feel embarrassed about it because actually I imagine there will be teachers who will be ‘oh I don’t want to teach that’. Or they don’t feel upskilled enough themselves or have the knowledge themselves….

Yeah especially when it’s female staff and male pupils

Ben > Yeah, yeah, yeah, yeah

Tess > Yeah yeah I think it’s that side of it as well and ensuring we have a role in that in actually being able to provide a training package or being able to provide something that gets them to feel empowered that maybe they CAN teach it and its not something they need to feel embarrassed about or worried about

Or shy away from…

Ben > So 21 years ago…. (calculating). So 21 years ago we did sex education and the girls and boys were separated and the girls went into explicit detail and had like hands on input about using condoms and things and the boys, we were just asked to name three body parts and then three slang words to describe…… and yes we did giggle but that was the end of the
RSE FOR YOUNG PEOPLE WITH ASD

467 lesson and then we did noughts and crosses for 40 minutes and the girls were pretty much
468 ready to...you know... off you go
469
470 Becca > I think that’s a reflection of, I know you were asking earlier about around what the
471 rules of the game are...currently...and I think part of that is around the lack of guidance
472 around what to teach and how to deliver but I think it’s probably like also a reflection of
473 gender and how that comes out within our education system and girls have this...Because I
474 had the same. Girls had to be separated and girls had some prac..., some practical ‘tooly’
475 things and boys had whatever boys had. But I think actually it’s coming at a time now when
476 people are starting to question how we understand gender and what that means for our
477 relationships so it would be interesting to see what the guidance does say...uhm...
478
479 Tess > In terms of guidance, in terms of things like gender and concepts like that that may
480 be difficult for the ASD population to kind of understand, in the guidance is there going to
481 be guidance around delivering this education to children with special educational needs? Is
482 that going to be within that? Is there guidance, you know are there going to be guidelines
483 for teachers or is it just a broad, is it just a general thing, ‘This is the policy, this is the
484 curriculum’. Or are teaching staff, you know support staff, going to be supported through
485 documentation as well because I think that’s you know, it’s making it very exclusive if it’s
486 not
487
488 Ben > Yeah cause if not, our input will probably be essential won’t it
489
490 Tess > Yeah. And I think that will have a massive impact on the roles of professionals and
491 potential within that ....so ...
492
493 Ok. Well guys thank you so much for your time. If there’s nothing else to add, I’d like to wrap
494 it up now as the room is needed. Thanks so much.
Appendix 19

Table of developing Themes
## Table of Developing Themes

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Appendix 20

Word Cloud of top 100 words used in data
Word Cloud of top 100 words used in data
Appendix 21
Word Tree showing data links to “Parents”
Word Tree showing data links to “Parents”

- a clause where, religious schools having discussions, but increasingly recently
- a degree, and I think a high school, we contacted
- a role for parents, links for all staff
- people panic, both schools and with children with ASD within reason, Yes ok.
- general agreeing then that what is your understanding, as as your role as a at schools and...and also, but would parents...how do comfortable with you...Carrie > Yes, facilitating in terms of...between
- Question 3: there is a role for that is alright
- I don’t know, but would is good to know that anybody else? Ron > Uhm...
- My can’t...please, don’t make particularly with autism, then involving relationship and sex education unless seems to be shared by staff John > Yeah. Question 4: tends to coincide with what the room. In terms of school, you mentioned it to say in relation to...uhm...a training presentation to follow. One or two to take guidance from his
- We have permission slips from an element of working you have shared that would generally ring up the because obviously...yeah. It’s of better coming from ok. Have you had there’s a role for
- but when you’re had a discussion I suppose it it’s more awkward. So doing it you spoken to by
Appendix 22

Word Tree showing data links to “Relationship”
Word Tree showing data links to “Relationship”

- a sexual relationship and
  - and what isn’t within
    - anybody so everyone has
      - he wants to start
        - may over time produce
          - the intimate part
              - of
                - understand the concept
                  - as far as:
                    - everything about relationship
                      - what
                        - the children understand
                          - what’s a friendship, what’s
                            - as far as a loving
                              - commitment? About what a
                                - She’s got a very
                                  - happy in a respectful trusting
                                    - have a stable, secure, safe,
                                      - perhaps have some sort
                                        - of
                                          - support him whatever type
                                            - pupil with autism that their
                                              - relationship
                                                - Like what’s a safe
                                                  - in the mainstream
                                                    - never taught any
                                                      - time to give
                                                        - family member, what’s a
                                                          - loving relationship goes, or
                                                            - sort of relationship, uh, professional
                                                              - as well as also
                                                                - changes, as well as
                                                                  - give to being in
                                                                    - of SRE to include
                                                                      - to the sex education, uh, ...
                                                                        - you can’t reference a normal

- if that’s what he wants...
  - they children with diagnosis | don’t
    - uh, ages, so legal ages, professional relationship with them
      - And yeah, that’s a, that’s
        - It could be with a
          - relationship with a
            - sex education in a
              - who do we have
                - before And you think ‘Ok
                  - Ben Yeah, I know, I’m
                    - from the point of view
                      - goes or sexual relationship, …, Ok, …
                        - in the future and uhmm, is
                          - about personal spaces, other children only
                            - different kinds of relationship it is, That’s what really
                              - looks like, not just what
                                - side of sex education and
                                  - that they will have with
                                    - they have with themselves as
                                      - a family member, what’s
                                        - partner. They’re there
                                          - with another person might be
                                            - already, uh, so
                                              - and they feel
                                                - you’re in … Having an understanding
                                                  - an understanding, do you even
                                                    - … Hmm a very comprehensive answer ….
                                                      - … Ok Carrie, > is that ok?
Appendix 23

Word Tree showing data links to “School”
Word Tree showing data links to “School”