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**I WISH I HAD LEARNT TO KEEP MYSELF SAFE – SEXUALITY
AND RELATIONSHIPS EDUCATION (SRE) FOR PUPILS WITH
AUTISTIC SPECTRUM CONDITION**

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Abstract

In recent years, in schools, sex and relationship education (SRE) has developed as a subject and become a bigger part of the National Curriculum in the UK. Indeed, 2020 sees the introduction of mandatory relationship education in all primary and secondary schools, and mandatory sex education in secondary schools. Although studies have explored some of the impact of autistic spectrum condition upon the use of SRE programmes, this has primarily centred upon attitudes of families and professionals.

This PhD attempted to explore the views and opinions of SRE from the point of view of both SRE co-ordinators and pupils with autistic spectrum condition. These were qualitative studies employing the use of 1:1 interviews with SRE co-ordinators from schools providing for pupils with autistic spectrum condition. This was followed by focus groups with pupils with autistic spectrum condition. The results suggested that the present SRE programmes being used within school were inadequate concerning the teaching of the more abstract socio-sexual world. This includes topics such as relationships, online world and consent. As a consequence, pupils with autistic spectrum condition felt unprepared for the wider world beyond school, including a feeling of vulnerability.

These two qualitative studies aided the development of an SRE programme which was implemented with two groups of pupils in two schools for pupils with autistic spectrum condition. Two measures were conducted with each pupil pre and post intervention. Results indicated improvements in the understanding of consent and abuse of the participants and some improvement in sexual knowledge. Although the results were positive, there were limitations affecting the generalisation of the programme. Such difficulties included the limited amount of pupils and schools within which the programme could be implemented, and the measures used. However, this study has provided a foundation for further research utilising further pilot sites.

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Thirdly, thank you to my family, for putting up with various articles, draft write ups and paper being strewn across the floor and table for the last six years. Also, for tolerating the ongoing discussions about sex education, my mumblings about what I needed to do, and the stresses involved. Finally, to my partner, Shirin, the biggest thank you. For half of our time together you have had to listen to me constantly talking and worrying about my research. Along the way you have listened to the good times and the stressful times. Without your support throughout my doctoral studies I am sure at times this thesis may not have existed.

Table of Contents

Chapter 1 – Introduction And Terminology Definition	1
1.1 Introduction	1
1.2 Definitions of intellectual and developmental disabilities, autistic spectrum condition and sexuality	3
1.2.1 Intellectual and Developmental Disabilities	4
1.2.2 Autistic Spectrum Condition and Asperger’s Syndrome	6
1.2.3 Mental health needs associated with Autistic Spectrum Condition	12
1.2.4 Social Difficulties and Autistic Spectrum Condition.....	13
1.3 What is Sexuality?	16
Chapter Two – Sexuality in relation to Intellectual and Developmental Disabilities and Autistic Spectrum Condition	22
2.1 Intellectual Disabilities and Sexuality	22
2.1.1. Historical Background: Eugenics Movement.....	22
2.1.2 Institutional Care and its Impact	24
2.1.3 Policies and legislation associated with sexuality and intellectual disability	27
2.1.4 Consent	29
2.1.5 Sex Offences Act 2003	31
2.2 Autistic Spectrum Condition and Sexuality	32
2.2.1 Adolescent development in teenagers with Autistic Spectrum Condition	32
2.2.2. Misconceptions	33
2.2.3 Social Impairments and the effect upon sexuality	35
2.2.4 Gender Identity and Autistic Spectrum Condition	40

2.3 Sexual Abuse and People with IDD and Autistic Spectrum Condition	43
2.3.1 Definition of Abuse	43
2.3.2 Occurrence of Abuse with People with IDD and Autistic Spectrum Condition	45
2.4 Conclusion	48
Chapter Three – Sex Education, Intellectual Disability and Autistic Spectrum Condition	49
3.1 Health Promotion	50
3.1.1 Health Belief Model (HBM)	50
3.1.2 Theory of Reasoned Action (TRA) and Theory of Planned Behaviour (TPB)	52
3.2 Sex Education – Programme Development	53
3.2.1 The Development of Sex Education within the UK	55
3.2.2 What has SRE become?	58
3.2.3 Sex Education and Intellectual and Developmental Disabilities	60
3.2.4 Sex Education and Autistic Spectrum Condition/Asperger’s Syndrome	64
3.2.5 Programme Evaluation	65
3.3 Systematic Literature Review	65
3.3.1 Search Methodology	66
3.3.2 Inclusion and exclusion Criteria	67
3.3.3 Analytical Process.....	68
3.3.4 Results	81
3.3.4.1 Sex Education Programme (Intellectual Disabilities General)	82
3.3.4.2 Impact of attitudes upon the implementation of sex education programmes	88

3.3.4.3 Specific impact of autistic spectrum condition/Asperger’s Syndrome on sex education programmes.....	95
3.4 Discussion.....	100
Chapter Four – Study One: The Provision of Sex and Relationship Education Programmes for Individuals with Autistic Spectrum Condition	103
4.1 Introduction	103
4.2 Method	107
4.2.1 Study Aims	107
4.2.2 Participants	107
4.2.3 Measures	109
4.2.3.1 Online Questionnaires	109
4.2.3.2 Face to Face Interviews	111
4.2.4 Procedure	114
4.2.5 Ethical Issues	116
4.2.6 Analysis	119
4.3 Results	124
4.3.1 Participant school characteristics and results of on-line survey	124
4.3.2 Interview Results	130
4.3.2.1 Over Arching Theme – SRE Battleground	131
4.3.2.2 Over Arching Theme – Resource and Support Abyss	142
4.3.2.3 Over Arching Theme – Attempts to provide positive SRE	155
4.4 Discussion	158

4.4.1 Methodological Limitations	160
Chapter Five – Study Two: The Perspective of Students with Autistic Spectrum Condition.....	162
5.1 Introduction	162
5.2 Developing Focus Groups	164
5.2.1 Recruitment	164
5.2.2 Environmental Factors	165
5.2.3 Interview Guide	165
5.2.4 Moderator	166
5.2.5 Data Collection and Analysis	166
5.2.6 Utilising Focus Groups with individuals who have IDD/autistic spectrum condition ...	168
5.3 Study Method	169
5.3.1 Study Aims	169
5.3.2 Ethical Issues	170
5.3.3 Participants	170
5.3.4 Consent	172
5.3.5 Process of the Focus Groups	174
5.3.6 Data Collection and Analysis	174
5.4 Results	176
5.4.1 Over Arching Theme – Knowledge Source	177
5.4.2 Over Arching Theme – Accessing the Knowledge	184
5.4.3 Over Arching Theme – All I want is to be safe	191
5.5 Discussion	196

5.5.1 Methodological Limitations	199
Chapter Six – Study Three: Sexuality and Relationships Education for People with Autistic Spectrum Condition – Pilot Programme Implementation	201
6.1 Introduction	201
6.2 The Need for a Pilot Study	201
6.2.1 Pilot Study Issues	202
6.3 Study Methodology	203
6.3.1 Study Design	203
6.3.2 Participants	203
6.3.3 Measures	204
6.3.4 Intervention	205
6.3.4.1 SRE Course Outline	206
6.3.5 Procedure	211
6.3.5.1 Ethics	211
6.3.5.2 Implementation	212
6.3.6 Analysis	212
6.4 Results	212
6.5 Discussion	214
6.5.1 Methodological Limitations	215
Chapter Seven: Conclusions and Implications for Practice	218
7.1 Review of Situation	219

7.2 Recommendations for Practice227

Reference.....229

APPENDICES

APPENDIX A - Masters in Autism Survey re: inappropriate sexualised behaviour.....	291
APPENDIX B - Study One Pre-interview questionnaire	301
APPENDIX C - Study One Interview Schedule.....	309
APPENDIX D - Study One Information Sheet	311
APPENDIX E - Study One Consent Form	315
APPENDIX F - Study One Ethical Approval Letter.....	317
APPENDIX G - Study Two Ethical Approval Letter.....	319
APPENDIX H - Study Two Participant Consent Form	321
APPENDIX I - Study Two Participant Information Sheet	325
APPENDIX J - Study Two School Information Sheet	331
APPENDIX K - Study Two School Assent Form	336
APPENDIX L - Study Two Parental Information Sheet	338
APPENDIX M - Study Two Parental Assent Form	343
APPENDIX N - Study Three Ethical Approval Letter	345
APPENDIX O - Study Three SRE Pilot Programme Outline	347
APPENDIX P - Study Three Participant Information Sheet	369
APPENDIX Q - Study Three Participant Consent Form	375
APPENDIX R - Study Three Parental Information Sheet	378
APPENDIX S - Study Three Parental Assent Form	383
APPENDIX T - Study Three School Information Sheet	385
APPENDIX U - Study Three School Assent Form	390

Table of Tables

<i>Table 3.1 - Key Concepts and Definitions of the Health Belief Model (Glanz et al, 2008)</i>	51
<i>Table 3.2 – Literature Review Results</i>	69-81
<i>Table 4.1 - Ethnic distribution for each participating school</i>	126
<i>Table 4.2 - Distribution of Diagnoses within each school</i>	127
<i>Table 4.3 – Distribution of Behaviour Type within each school</i>	128
<i>Table 6.1 - Results of Wilcoxon matched pairs signed ranks test for pre and post intervention scores</i>	213

Table of Figures

<i>Figure 1.1 - Definition and main descriptors of intellectual developmental disorders (IDD) agreed by the ICD Working Group (Carulla et al, 2011).....</i>	<i>5</i>
<i>Figure 1.2 - The Triad of Impairments.....</i>	<i>7</i>
<i>Figure 1.3 - DSM-IV Diagnostic Criteria for Autistic Spectrum Disorder and Asperger's Syndrome.....</i>	<i>9</i>
<i>Figure 2.1 – Urinal Etiquette adapted from Lynne Moxon's etiquette(Moxon, 2016)</i>	<i>38</i>
<i>Figure 3.1 - Flowchart outlining article results for literature review.....</i>	<i>68</i>
<i>Figure 4.1 - School response rates in author's MA dissertation.....</i>	<i>110</i>
<i>Figure 4.2 - Total Numbers of pupils in each age group within schools</i>	<i>126</i>
<i>Figure 4.3 - Support Services Accessed by schools to support pupils' behaviours.....</i>	<i>129</i>
<i>Fig. 4.4 – Interview Themes.....</i>	<i>131</i>
<i>Fig. 5.1 – Focus Group Themes.....</i>	<i>176</i>
<i>Fig. 6.1 – Man at the Crossroads Visual (with permission to use, The Good Way Model, Ayland, 2006).....</i>	<i>207</i>
<i>Fig. 6.2 – Circle of Relationships Visual Material (SOTSEC-ID, 2017).....</i>	<i>210</i>

CHAPTER ONE

INTRODUCTION AND TERMINOLOGY DEFINITION

1.1 Introduction

There has long been public concern about sexual behaviour as a public health issue, and since the 1950s there has been a general attempt to provide sex education to children. As part of the national curriculum, the implementation of a Sex and Relationship Education (SRE) programme has become mandatory for schools since 1993. However, even though legislation stated that local authority-maintained schools (presently not academies or free schools) in England have an obligation to provide such programmes, no specific structure has been provided. The lack of structure and inconsistencies between schools in the implementation of the programmes was highlighted in the “Not Yet Good Enough” report by Ofsted (2013), which highlighted concerns regarding the SRE programmes provided within schools:

“Sex and relationships education required improvement in over a third of schools. In primary schools this was because too much emphasis was placed on friendships and relationships, leaving pupils ill-prepared for physical and emotional changes during puberty, which many begin to experience before they reach secondary school. In secondary schools it was because too much emphasis was placed on ‘the mechanics’ of reproduction and too little on relationships, sexuality, the influence of pornography on students’ understanding of healthy sexual relationships, dealing with emotions and staying safe.”

Ofsted, 2013, p6-7

Although Ofsted highlighted the inconsistencies in the SRE programmes between schools, the continued governmental investment in such education has contributed toward an improvement (i.e. a lowering) of conception rates for under 18s. The Office for National Statistics found that in 2015 in England and Wales, 20,351 young women aged under 18 had conceived a child (ONS, 2017) compared to 2014 when the number totalled 22,653. In contrast, there has been a steady increase year upon year in diagnoses of certain sexually transmitted diseases such as syphilis and gonorrhoea (Public Health Report, 2018). Such differences may be indicative of the views held by those under 18, as

highlighted within the ONS report. These include a change in perception of those under 18 about becoming a single mother or having a greater focus upon their future and aspirations but with no consideration of the sexual health aspects of the situation. As an attempt to further improve the situation regarding SRE programmes, the Education Secretary, Justine Greening, in 2017 announced reforms in SRE which are due to be mandatory for all schools to implement from September 2020. Now calling it Relationships and Sex Education (RSE), it includes mandatory relationship education within primary schools and mandatory sex education within secondary schools. The new relationship curriculum, which Justine Greening argued would reflect the ongoing changes in the modern world, will cover 'Families and people who care for me', 'Caring friendships', 'Respectful relationships', 'Online Relationships', and 'Being Safe'. It is hoped that primary school pupils will develop the understanding and ability to report concerns about abuse. Regarding the sex education aspect, although it is not mandatory in primary schools, there should be some form of sex education that is appropriate to pupils' ages, and physical and emotional maturity. However, the aim should be to prepare pupils for the changes that occur within puberty. The secondary school programme should then continue the process started in primary schools.

Whatever the case for relationships and sex education for the majority of children, there has been remarkably little attention paid to those with special needs (Murphy, 2016). As highlighted during the Westminster Education Forum regarding SRE/RSE (2018), Ian Bauckman, advisor to the government, discussed the need for further consultation regarding improving the SRE programmes for individuals with intellectual and developmental disabilities and/or Autistic Spectrum Condition. Such consultation is important when considering those individuals with intellectual disabilities, particularly those with Autistic Spectrum Condition, as studies have shown that lower levels of knowledge and understanding about sexual issues and abuse are present in these groups (Konstantareas & Lunskey, 1997; McCabe, 1999; Murphy & O'Callaghan, 2004; Ousley & Mesibov, 1991).

Lacking an appropriate level of understanding concerning sexual and relationship knowledge has been long postulated to be one of the factors relating to the display of inappropriate sexualised

behaviour in people with intellectual disabilities (Martinello, 2015). This has also been documented within the literature concerning treatment plans and support for male sex offenders with intellectual disabilities (Hingsburger et al, 1991). In a practical sense, the present author's experience of working with both adults and adolescent boys and girls with intellectual and developmental disabilities, Autistic Spectrum Disorder and/or Asperger's Syndrome has continuously highlighted the consequences to shortfalls within the education of such topics. Often it seems that the common element involved with this group centres upon either the lack of sex education or difficulties with its implementation. In this author's role as an Independent Special Needs Advisor, frequently support is being given to individuals who have displayed inappropriate sexualised and potentially offending behaviour. For many, it is the case that there has been no sex education or a lack of understanding concerning the content, but why is that and what occurs when things go wrong?

The following studies will explore these issues, but specifically in relation to both young men and women with Autistic Spectrum Condition or Asperger's Syndrome, as this is predominantly the people the author regularly supports. This exploration will include the examination of the development of sex education in the mainstream, intellectual and developmental disabilities and Autistic Spectrum Condition/Asperger's Syndrome arenas. This will include an examination sex education programmes used by a number of schools and also the support available if problems should occur. In addition, young people with autistic spectrum condition themselves are interviewed about their experience of sex education, and finally, a trial sex education programme will be delivered and evaluated in two schools for young people with autistic spectrum condition.

1.2 Definitions of intellectual and developmental disabilities, autistic spectrum condition and sexuality

Before progressing further, clarification of the central terminology utilised within the thesis will be outlined to provide the reader with some context.

1.2.1 Intellectual and Developmental Disabilities

Intellectual and Developmental Disabilities is the latest term in a long line of terms, including “mental subnormality”, “mental handicap” and “learning disability”, and as these have changed so have the various components of the diagnostic criteria. The Department of Health in England (DH 2001) definition for a learning disability, which many services now utilise for intellectual and developmental disability, is:

- A significantly reduced ability to understand new or complex information, to learn new skills (impaired intelligence) along with a reduced ability to cope independently (impaired social functioning).
- The onset of disability is considered to have started before adulthood, with a lasting effect on development.
- This definition includes IQ and functional aspects that make it distinct from the use of the term "learning difficulties" which has a far wider application in education

(DH 2001)

In addition to the Department of Health, the use of the term “intellectual disabilities” and “developmental disabilities” were also discussed by the World Health Organization (WHO)’s International Classification of Diseases (ICD) Working Group as a replacement for the previously widely used term “mental retardation” (Salvador-Carulla et al, 2011). The replacement with ‘intellectual and developmental disabilities’ (IDD) occurred as the term was found to be favoured in most countries as well as being more acceptable in most policy and clinical situations. As part of this acceptance, the Working Group proposed a specific definition for intellectual and developmental disabilities as shown in Table 1.

Definition

A group of developmental conditions characterized by significant impairment of cognitive functions, which are associated with limitations of learning, adaptive behaviour and skills.

Main descriptors

- IDD is characterized by a marked impairment of core cognitive functions necessary for the development of knowledge, reasoning, and symbolic representation of the level expected of one's age peers, cultural and community environment. Nevertheless, very different patterns of cognitive impairments appear for particular conditions of intellectual and developmental disabilities.
- In general, persons with IDD have difficulties with verbal comprehension, perceptual reasoning, working memory and processing speed.
- The cognitive impairment in persons with IDD is associated to difficulties in different domains of learning, including academic and practical knowledge.
- Persons with IDD typically manifest difficulties in adaptive behaviour; that is, meeting the demands of daily life expected for one's age peers, cultural, and community environment. These difficulties include limitations in relevant conceptual, social, and practical skills.
- Persons with IDD often have difficulties in managing their behaviour, emotions, and interpersonal relationships, and maintaining motivation in the learning process.
- IDD is a life span condition requiring consideration of developmental stages and life transitions.

Fig. 1.1 - Definition and main descriptors of intellectual developmental disorders (IDD) agreed by the ICD Working Group

Carulla et al, 2011

The term "intellectual disabilities" has been described by the ICD Working Group as being on a continuum which includes subcategories to describe the wide range of different abilities and their impact. The terminology utilised in this continuum is "mild", "moderate" and "severe" or "profound" to distinguish between the different levels, although these may not necessarily adequately describe the range of impairments or disabilities that may be experienced by this group. The details of the individual categories are:

- **Profound**

People with profound intellectual and multiple disabilities (PMID), are often the most disabled people in the community. From an intellectual point of view their Intelligence quotient (IQ) is under 20 resulting in severely limited understanding. Physically this group of people may have

a range of multiple disabilities which require additional support as well as frequently having limited understanding and communication methods.

- **Severe**

People in this category often have limited communication although they can use basic words and gestures. Their support needs are high in relation to everyday activities, but many are able to deal with some of their personal care needs.

- **Moderate**

People with moderate intellectual disabilities are more likely to possess a higher level of communication skills and may require some support in relation to caring for themselves.

- **Mild**

Many people with mild intellectual disabilities are able to communicate their needs effectively and are often independent in many areas of their daily lives. However, support may be required for more abstract or complex situations. Many people with mild intellectual disabilities are undiagnosed.

P6, Hardie & Tilly, 2012

In practice, these categories can be deceiving, especially concerning someone with Autistic Spectrum Condition, for example, who may technically have a mild intellectual disability but who displays an uneven skill profile leading to them appearing to have more moderate than mild learning disabilities in terms of their social skills. This may contrast to them being able to look after their own personal care and everyday needs quite independently (RCN 2010). The range in the diagnostic criteria methods and services for people with intellectual disabilities are wide and dependent upon the agency and/or country (Holland et al, 2002).

1.2.2 Autistic Spectrum Condition and Asperger's Syndrome

As with Intellectual and Developmental Disabilities, Autistic Spectrum Condition¹ is one of a range of terms used concerning the term "Autism" was first identified as "early infantile autism" by Kanner in 1943 (Kanner, 1943). Kanner's criteria for diagnosis were social aloofness and elaborate repetitive

¹ The term "Autistic Spectrum Condition" can some times be written in the plural ("Autistic Spectrum Conditions"). There presently is no clear rule regarding which version is correct. For the sake of this thesis, the singular term will be used.

routines. Subsequent studies have shown that autism is closely related to a range of developmental disorders, including Asperger's syndrome (Gillberg, 1998; Wing, 1981). In 1978 the “Camberwell Study” was undertaken by Lorna Wing and Judy Gould to identify the prevalence of Kanner’s Autism amongst children known to have special needs within the London Borough of Camberwell (Wing & Gould, 1979), and they showed that of those children with an IQ under 70 nearly 5 per 10,000 had Kanner’s Autism. In addition to this prevalence rate, Wing and Gould identified a larger group of children beyond the Kanner Autism group that demonstrated a range of impairments that placed them within the broader “autistic spectrum”. Consequently, the concept of “The Triad of Impairments” was proposed and is still used today as part of the diagnostic process over three decades later. The Triad of Impairments refers to a triad of impaired social interaction, communication, and imagination, associated with a rigid, repetitive pattern of behaviour. (See illustration in Fig. 2)

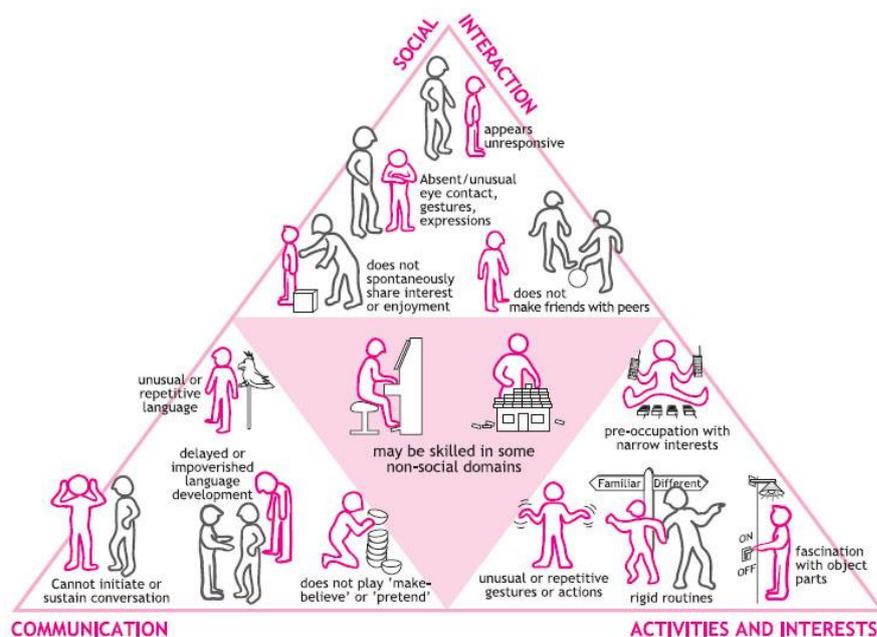


Fig 1.2 - The Triad of Impairments

With thanks to the National Autistic Society

The onset of autistic spectrum condition is during the first three years of life, but problems can often be observed only later in childhood. In contrast to Autism, Asperger’s Syndrome describes a specific group of people with autistic spectrum condition characterised by a lack of general delay of spoken or receptive language or cognitive development up to the age of 3. They show abnormalities in social

interaction including a preference for isolation or naïve approaches; intensive interest in only one or two subjects; a narrow, repetitive lifestyle; and poor motor coordination (Ehlers Gillberg & Wing, 1999). They are nevertheless included under autistic spectrum condition and several studies have shown Autism and autistic spectrum condition to be indistinguishable later in life (Howlin, 2004).

In 2011, the National Institute for Health and Clinical Excellence (NICE) issued a set of guidelines relating to the diagnosis of autism in children and young people followed in 2012 by guidelines relating to the diagnosis of autistic spectrum condition in adults. These outline guidance for service providers relating to the recommended process for effective assessment and diagnosis of autistic spectrum condition. Central to this process is the use of autism-specific assessment tools based upon the criteria outlined in either the Diagnostic or Statistical Manual of Mental Disorders (DSM IV, 2000) or the World Health Organisation's International Classification of Diseases (ICD-10, 1992). Both sets of criteria are internationally recognised and possess a number of similarities. DSM IV provides a detailed assessment that takes into account some of the areas highlighted within the Triad of Impairment (See Fig. 3 for specific criteria).

In 2013, DSM-4 was revised and DSM-5 introduced. Within this new version, several changes were made to the diagnostic criteria for AUTISTIC SPECTRUM CONDITION and Asperger's Syndrome:

- Merging of previous diagnostic terms used in DSM-IV ('autistic disorder', 'Asperger's disorder', 'childhood disintegrative disorder' and 'PDD-NOS (pervasive developmental disorder not otherwise specified)'). Consequently, any future diagnosis given will be one of 'autism spectrum disorder (autistic spectrum condition)'.
 - social communication and interaction
 - restricted, repetitive patterns of behaviour, interests, or activities.
- The reduction of the areas of impairment from three to two:
- The inclusion of sensory behaviours and 'social communication disorder'.
- More emphasis during diagnosis upon the person's needs and the potential impact upon their life.

Similar changes are being indicated in the forthcoming update of the ICD-10 when the new ICD-11 is introduced initially in 2017(Lord and Jones, 2012), but now moved to 2022. As a consequence to the changes, Asperger's Syndrome will only be used within this thesis when referred to by others. Otherwise, only Autistic Spectrum Condition or Autistic Spectrum Disorder will be utilised.

<p>(I) A total of six (or more) items from (A), (B), and (C), with at least two from (A), and one each from (B) and (C)</p> <p>(A) qualitative impairment in social interaction, as manifested by at least two of the following:</p> <ol style="list-style-type: none"> 1. marked impairments in the use of multiple nonverbal behaviors such as eye-to-eye gaze, facial expression, body posture, and gestures to regulate social interaction 2. failure to develop peer relationships appropriate to developmental level 3. a lack of spontaneous seeking to share enjoyment, interests, or achievements with other people, (e.g., by a lack of showing, bringing, or pointing out objects of interest to other people) 4. lack of social or emotional reciprocity (note: in the description, it gives the following as examples: not actively participating in simple social play or games, preferring solitary activities, or involving others in activities only as tools or "mechanical" aids) <p>(B) qualitative impairments in communication as manifested by at least one of the following:</p> <ol style="list-style-type: none"> 1. delay in, or total lack of, the development of spoken language (not accompanied by an attempt to compensate through alternative modes of communication such as gesture or mime) 2. in individuals with adequate speech, marked impairment in the ability to initiate or sustain a conversation with others 3. stereotyped and repetitive use of language or idiosyncratic language 4. lack of varied, spontaneous make-believe play or social imitative play appropriate to developmental level <p>(C) restricted repetitive and stereotyped patterns of behavior, interests and activities, as manifested by at least two of the following:</p> <ol style="list-style-type: none"> 1. encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity or focus 2. apparently inflexible adherence to specific, nonfunctional routines or rituals 3. stereotyped and repetitive motor mannerisms (e.g hand or finger flapping or twisting, or complex whole-body movements) 4. persistent preoccupation with parts of objects <p>(II) Delays or abnormal functioning in at least one of the following areas, with onset prior to age 3 years:</p> <p>(A) social interaction (B) language as used in social communication (C) symbolic or imaginative play</p> <p>(III) The disturbance is not better accounted for by Rett's Disorder or Childhood Disintegrative Disorder</p>
--

Fig 1.3 – DSM-IV Diagnostic Criteria for Autistic Spectrum Disorder and Asperger's Syndrome

Concerning specific diagnostic instruments, there has been increased interest in their reliability and validity. Although all such diagnostic instruments aim to gather appropriate information for the diagnosis of autistic spectrum condition, the approaches used in the assessments vary (Mazefsky & Oswald, 2006). The Autism Diagnostic Schedule Second Edition (ADOS- 2: Lord et al, 2012) is a semi-structured, standardised observational assessment tool designed to examine a child's behaviour via

their communication, social interaction and play, including any displayed restrictive or repetitive behaviour. This is then measured in a number of domains, including the ability of the child to tell a story. It utilises a new diagnostic algorithm to generate a score leading to a potential diagnosis. The results provide the assessor with an indication as to the likelihood that the child meets the criteria for one of three classifications: Autism, Autistic Spectrum, and Non-Spectrum including the severity of the individual's autistic symptomology.

It is important to highlight that the category of Asperger's Syndrome is not included as part of the outcomes following the changes in diagnostic criteria in ICD-10. However, in practice the assessing professional bases their decision upon a full range of information (Roth, 2010), including a developmental interview schedule such as the Autism Diagnostic Interview-Revised (ADI: Lord et al, 1994). The Autism Diagnostic Interview is a standardised interview schedule used with parents/caregivers consisting of almost a hundred questions based broadly upon the criteria outlined in DSM-V and ICD-10. In contrast to the ADOS, ADI only provides a cut off for autism and does not explore other conditions that may be present. Due to the number of questions, completion of the ADI can be considerably lengthy and, as highlighted in a study by Chakrabarti and Fombonne (2001) when compared to the judgement of experienced paediatricians, the ADI did not necessarily enhance the diagnostic process. A broader diagnostic tool is the Diagnostic Interview for Social and Communication Disorders (DISCO (Leekam et al, 2002; Wing et al, 2002)) which, as with the ADOS, utilises algorithms to identify a range of disorders as well as autistic spectrum condition. Originally developed by Lorna Wing and Judith Gould, the DISCO is more dimensional in nature which contrasts the ADI's "yes or no" diagnostic outcomes and provides indications of where a person is in relation to the autistic spectrum. However, both the ADI and DISCO interviews are very lengthy (about 1½ hours).

There are also some briefer questionnaire measures of Autism/autistic spectrum condition such as the Gilliam Autism Rating Scale (GARS: Gilliam, 1995), Social Communication Questionnaire (SCQ: Rutter, Bailey & Lord, 2003) and the Autism-Spectrum Quotient (AQ; Baron-Cohen et al, 2001). The Gilliam Autism Rating Scale (GARS: Gilliam, 1995) focuses on providing an overall autism rating to indicate the likelihood of autism. This is achieved via a parent questionnaire covering stereotypical

behaviours, communication, social interaction and developmental issues. However, there are issues relating to the validity of the GARS due to limited studies into its usage. From those that have been performed, the results have proven contradictory (Gilliam, 1995; South et al, 2002). The SCQ is a brief parental report questionnaire used in the screening of autistic spectrum condition associated symptoms (Rutter, Bailey and Lord, 2003). It is based upon the Autism Screening Questionnaire (Berument et al, 1999) and is valid in identifying symptoms associated with autistic spectrum condition in children 4 years of age and older (Berument et al, 1999). Studies have investigated the SCQ being used with younger children, but these have proven inconclusive (Wiggins et al, 2007). The questionnaire comprises of 40 questions that parents answer in relation to observable behaviours exhibited by their child. Ideally, the questionnaire should take about 15 minutes for the parent to answer and then be scored by the clinician. The Autism Spectrum Quotient (AQ) of Baron-Cohen and colleagues is a self-reporting tool for assessing the number of autistic traits an individual possesses. As with the SCQ, the AQ is comprised of several questions (50) examining behaviours being displayed. Initially, the AQ was devised for adults but further studies (Woodbury-Smith, Robinson and Baron-Cohen, 2005; Baron-Cohen et al, 2006) have indicated some validity in its use with adolescents. Although the studies have indicated the usefulness of the AQ in the assessment process, difficulties have arisen when the individual completing the questionnaire himself/herself has issues that impair their accuracy in self-awareness, e.g. severe social deficits or intellectual impairment (Baron-Cohen et al, 2006). As such, the AQ has not been used as a general population screening tool as adaptation may be required concerning the scoring threshold due to these deficits.

The importance of a diagnosis can be the validation of parental views, as well as the potential for access to relevant support and services (Stehli, 1995). However, how can this be effectively achieved with such a range of tools? What is the gold standard? Each tool possesses positives and negatives; however comparative studies have not necessarily identified any one as the gold standard. One study comparing ADOS, ADI, GARS and diagnoses made through team observations (Mazefsky & Oswald, 2006) highlighted that a potential gold standard was more about having a consensus of opinion between at least two experts. The researchers identified several limitations of the study, including the knowledge and emotional acceptance about the situation possessed by the parents impacting upon the answers they provided. However, these limitations are also relevant to the individual

assessment tool on a daily basis, so that the attainment of a perfect tool is probably impossible. This perception that no one diagnostic tool is gold standard has also been included within both the NICE Pathways for diagnosing in under 19s and adults. The Pathways bring together a range of sources regarding appropriate methodology to assessing such individuals and states that an assessor should “not rely on any autism-specific diagnostic tool alone to diagnose autism” (NICE, 2018) but should use all sources of information, including their own clinical judgement when making a diagnosis. In contrast, the NICE Guidance for diagnosing autistic spectrum disorder in adults recommends the use of the DISCO, ADOS-G or ADI-R for a more complex and comprehensive assessment of the condition (NICE, 2018).

1.2.3 Mental health needs associated with Autistic Spectrum Condition

Since 1970 it has been noted that people with Autistic Spectrum Condition and especially those diagnosed with Asperger’s Syndrome are at a high risk of suffering from depressive episodes (Rutter, 1970). Additionally, two studies in 1981(Wing) and 1985 (Rumsey et al) found that a high proportion of people with autistic spectrum condition, especially relatively high-functioning individuals, suffered from generalised anxiety problems which can be exacerbated by those problems associated with the onset of adolescence and puberty. Primarily it has been recognised that a proportion of these mental health conditions have root causes in a lack of social skills (Ghaziuddin & Greden, 1998), due to our dependency upon our relationships providing each of us with a sense of worth and well-being (Rothenberg, 1999). This is further supported by Attwood (2000) who feels that the resulting mental health conditions can also be attributed to an increased awareness by the person with Asperger’s Syndrome concerning their isolation and inadequate social skills. Even in cases where the person seems unaware of their condition, it has been shown that even without this insight many people with Asperger’s Syndrome still possessed some degree of realisation that they had difficulties in the area of social skills (Portway & Johnson, 2005). However, the study did speculate that this potential insight that was demonstrated in the participants could also be due to the attitude and behaviour of those around them in response to the person’s differences which, in turn, had a negative impact upon the person with Asperger’s Syndrome.

Frequently studies have shown how the impact of Asperger's Syndrome upon a person and their abilities to deal with the world can cause an increase in anxiety and subsequent behavioural disturbances (Sofronoff et al, 2005; Russell & Sofronoff, 2004). This increase in the levels of both mood and anxiety problems in people with Asperger's Syndrome is in comparison to the rest of the general population and often manifests itself in the form of aggressive behaviour both externally and internally. Such behaviours have been highlighted by a range of studies which describe issues including:

- A tendency to withdraw from the general social circle (Bildt, 2005)
- General aggression and "unmanageable behaviour" (Lewis et al, 2005)
- Perceived loneliness (Bauminger et al, 2000)
- Increased ritualistic behaviour (Sofronoff et al, 2005)
- "Insolent" and "uncooperative" behaviour with adults, especially in the school setting (Gilmour et al, 2004).

Unfortunately, the consequence of such behaviours is to highlight that the person with autistic spectrum condition has difficulties placing them in a vulnerable situation, including ridicule by those around them (Portway and Johnson, 2005).

1.2.4 Social Difficulties and Autistic Spectrum Condition

Russell and Sofronoff's (2004) study highlighted the impact of increased anxiety and social worries on the person with autistic spectrum condition, including a range of symptoms such as panic, agoraphobia and Obsessive Compulsive Disorder, as well as, according to Portway and Johnson (2005), an increased incidence of suicidal thoughts as a way of dealing with the world around them.

Bildt (2005) highlighted how the person with Asperger's Syndrome not only possesses the difficulties in their social learning but also experience difficulties over a range of issues which impact upon their social skill development. These included:

- recognition and understanding of emotions in themselves and others,

- changes in routine and expectations in the world around them,
- a lack of insight into the social difficulties associated with their syndrome
- repetitive rituals
- possessing sufficient social skills to be able to effectively participate in social situations.

The issues raised by Bildt were further discussed in a study by Sofronoff et al (2005) which demonstrated how the person with Asperger's Syndrome could be clumsy and inappropriate in many types of social contact, including the inability to read social cues during contact and being unable to respond appropriately. Often the content of the conversation involving a person with Asperger's Syndrome can be narrow and the content reflects the person's specific interests or obsessions. This type of conversation can then be carried on by the person with no regard for the listener or any social cues that may be given as a way to terminate the situation. This was felt by Sofronoff to reflect an element of obsessive-compulsive disorder associated with someone who has Asperger's Syndrome.

Although not immediately seen as a lack of social skills, the issue of resistance to change for a person with Asperger's Syndrome has arisen in some studies, particularly Russell and Sofronoff's (2004) which illustrated how unplanned change proved to have an increasing impact upon the person, as it can be present throughout their day and lives. It is also often an issue that is unavoidable no matter how much planning takes place. The types of changes identified by the study were not only about routine but also about the person's expectations about a situation, apprehension in social situations and environmental changes no matter how small. Any such changes that may occur can frequently result in increased uncertainty and anxiety for that person. This is especially relevant when it is felt by some that the person's need for routine and ritualistic, repetitive behaviour may be a form of providing structure to the person in what is perceived as a chaotic world (e.g. Attwood, 2000).

The impact of inappropriate and inadequate social skills has been raised as a contributing factor in relation to the bullying of the person with autistic spectrum condition, and figures in one study illustrated how four out of five children with Asperger's Syndrome being educated in mainstream schools were unhappy (Lewis et al, 2005). The two main reasons for this, given by those with autistic

spectrum condition were bullying which accounted for 21% and teasing 61%. The occurrence of bullying further adds to the anxiety being experienced by this group of people as they attempt to live within the neuro-typical world. Bullying can occur for a variety of reasons but in relation to people with autistic spectrum condition it is often linked to their limited social abilities and the associated misunderstandings by both the person with autistic spectrum condition and those around them. Concerning the former, Portway and Johnson (2005) identified possible causes as involving the person's understanding of the purpose of school and how hectic school life can be which places high anxieties upon the individual with autistic spectrum condition. This is especially relevant to the social side of school life, and most predominantly in the later years when it was felt that differences became more obvious. An example from the research is a quote from one of the participants:

Five girls followed me about, calling names, pushing me, pulling my hair. It's because I was odd. I always felt alone and never had any real friends, but actually I found it easier when I was left on my own. (Rachel aged 31)

P 78, Portway & Johnson, 2005

This invariably leads to a feeling of "not fitting in" on the part of the person with autistic spectrum condition, resulting in extreme or "bizarre" behaviour changes including self-enforced loneliness and isolation. In relation to those around them, bullying can happen to anyone but those more vulnerable or different are more likely to become victims. The lack of efficient social skills in people with autistic spectrum condition frequently includes the lack of more subtle skills in those areas relating to gullibility, naiveté or avoiding victimisation. This immediately places them in a difficult position as they may be unable to recognise the intentions of a person's action, whether good or bad (Bildt, 2005). This can be further impacted upon if the person with autistic spectrum condition exhibits any extreme behaviour either generally or as a result of the interactions they experience. As a consequence, the evidence demonstrates that the occurrences of bullying for this group of people, whatever the age is high and can further impact upon the mental health and anxiety of the person with autistic spectrum condition.

The impact and associated vulnerability linked with social skills issues go beyond the realms of bullying and appropriate interaction. The ability to develop relationships, both friendships and intimate relationships, are impeded and without the appropriate knowledge and intervention can result in more than anxiety. The need to understand social skills and etiquette can also result in the involvement of the Criminal Justice System because legal boundaries have been inappropriately crossed. To reduce this possibility and so the person's vulnerability, there is a need to teach such knowledge and skills using scientific and structured approaches rather than just relying upon natural acquisition (Hellemans et al, 2007). However, as the "Not Yet Good Enough" report by Ofsted (2018) discussed, there is a general shortfall in sex and relationship education, particularly regarding friendships and relationships. This results in individuals having to learn these skills independently rather than how Hellemans et al (2007) suggests.

1.3 What is Sexuality?

The transition from child to adolescent to adult has always been present, although it is only since the beginning of the twentieth century that the term "adolescence" was widely used (Locke & Bogin, 2006). As part of adolescence, the issue of sexuality has been seen as an important aspect of the developing teenager (Bay-Cheng, 2003). However, the notion of adolescent sexuality and the "norms" involved in a person's development are less clear.

Sexuality has been identified as an important and integral part of human life, so important as to be included in a range of conceptual frameworks of care (Roper et al, 1990). However, the definition of such a concept has proven potentially difficult due to the breadth and variability of interpretations of what constitutes sexuality (Sheerin & McKenna, 2000), along with the influences that are present in society, including socio-economic, political, religious and spiritual (WHO, 2002). Some of the influences will be discussed in greater detail in later chapters, such as historical changes in attitude toward such subjects (Pilcher, 2005), and the attitude toward sexuality and people with intellectual disabilities, autistic spectrum condition. Cultural influences also have a marked impact upon the understanding about sexuality (Katoda, 1993) which can limit or expand upon what is seen as

sexuality. Theoretically, the development of teenage adolescence and their sexuality has been explored by several people.

Essentialist Theory

From a biological point of view, the changes involved when going through puberty, including hormonal, physical changes and developing identity often comes with an 'inner war' (Erikson, 1968) during which the teenager is struggling with such changes. Such beliefs have been part of the essentialism approach toward sexuality (Bay-Cheng, 2003) resulting in the perception that sexuality is more instinctual with teenagers being driven by sexual desires and needs (Lesko, 1996), with an underlying drive for species survival (Moore & Rosenthal, 2007) which is seen as inevitable and neutral (DeLamater & Hyde, 1998) but which requires social mediators, such as societal morals and law, in order for the adolescent to gain control. Essentialist theorists perceive the sexual development of teenagers from two perspectives; evolutionary and psychosexual. The basis of the evolutionary theory can be perceived as a person's sexuality is all about their genes and is very much based upon species survival. Such ideas have origins with the work of Darwin's (1871) understanding of evolution, including issues relating to "mating" and selection of certain individual characteristics. Additionally, some researchers have expanded upon the selection process by stating that females often choose partners depending upon the partner's ability to parent effectively (Trivers and Campbell, 1972).

An alternative essentialist theory is very much based upon the work of Freud (both Sigmund and his daughter, Anna) who explored the development of adolescence from a psychosexual perspective. As with the evolutionary theory, Freud (1905) theorised that the motivations for our behaviours, including sexual libido, originated in our unconscious. Freud felt that the nature of the human mind could lead to actions and decisions being made concerning sexuality (e.g. sexual attraction and belief) regardless of any conflict with social taboos. As with much of Freud's beliefs regarding the psychological development of an individual, it was postulated that the psychosexual development reaches its maximum after puberty (the genital stage). Later work by Anna Freud (1969) focussed more on the adolescent development and how sexual development in adolescence occurs

unconsciously during a time of upheaval due to the surge of hormones that occur during this period of a person's life. Further work by Blos (1988) looked at how the adolescent needs to sever emotional bonds with parents in order to meet sexual needs outside the family unit. This emotional need was perceived by Blos as being primary whilst physical changes were secondary and inevitable to the developmental process.

This psychosexual construct of teenagers being nothing but deficient and dangerous has led to the approach toward sex education being more about protection or early intervention. Such perceptions can be witnessed in the approach toward teaching safer sex topics, such as AIDS (A Nation at Risk, 1983), within which the aim was to highlight the consequences of practising unsafe sex. However, do such approaches provide the teenager with the understanding required to effectively develop within modern society? Reviews of the literature (Marston and King, 2006) indicate that such approaches are becoming ineffective potentially due to the changing social and cultural landscape surrounding teenagers. Consequently, as time has marched on, the concept of social constructionism which examines the impact of the surrounding world and environment developed.

Social constructionism

The idea that a person's developing sexuality and self-image comes as a result of factors around them has been examined by many. Foucault (1978) argued that the sexual development of an individual is more than just the biological drive but is affected by their environment. Using logic developed from Winnicott's (1992) idea surrounding the developing baby, Gilbert suggested that "there is no such thing as an adolescent", but that the adolescent develops according to the environmental influences such as peer groups, family and school. Further studies highlighted how such influences not only impact upon the development of the adolescent's sexual behaviour but that such influences are common amongst many cultures and beliefs (Marston and King, 2006; Widmer et al, 1998). These environmental effects can impact everything from sexual behaviour, age of first sexual experience and even the sexual language used by people. For example, it is theorised that we have various types of language for sexual activity and sexual bodily parts. These languages depend upon the situation – 'coarse language', 'romantic language' or 'scientific language' (Moore and Rosenthal, 2007), all of

which can develop depending upon the trends and cultural elements being utilised by adolescents at the time. In modern times, the intervention of mass media has potentially been a key factor that has impacted upon the development of adolescent sexuality, with studies identifying adolescents as using some form of media up to seven hours a day (Roberts et al, 2004). Amongst this usage, the adolescent will be exposed to a range of sexual imagery, including within programmes aimed at teenagers. In addition, the rise of social media and ever-increasing methods of communicating has further impacted upon the issue of peer groups and subsequent peer pressure. Twenty-four-hour access to a wider global peer group, much of which can contain content that can be anonymised or falsified, has resulted in perceived sociocultural norms changing rapidly, sometimes for the worse (Litt & Stock, 2011)). This influence has been seen in relation to teenage sexuality and development. Brown et al (2006) examined the influence of mass media upon such development and identified that the impact of media was significant in affecting the early adolescent's sexual intentions and behaviours far more than most other influences, including parental involvement. However, often this influence is missing key aspects of sexual development, such as potential negative consequences and preventative measures (Kunkel et al, 1999), resulting in an individual being more likely to learn more aggressive sexual behaviours (Zillman, 2000). Such patterns of behaviour imitation and modelling have been discussed within the Cognitive Social Learning Theory which has explored how such imitation often occurs when the subsequent behaviour is either rewarded or not punished, or the source of the behaviour is perceived by others as attractive (Bandura, 1994). Within the realms of media influence, the use of "attractive characters" partaking in such pleasurable activities as sex with no negative consequences reinforces this concept.

Although the constructionism approach provides a potentially more realistic view of the modern adolescent development, it is unrealistic to solely base adolescent sexual development upon these concepts (Moore & Rosenthal, 2007). The individuality of the developing human being and associated sexuality means that it would be impossible for such theories to fully incorporate all aspects of sexual development. Such individuality within sexual development also has an impact on how external methods, specifically sex education and health promotion are implemented. Kijak (2013) expanded upon the concept by utilising what had been identified by WHO in relation to

sexuality. Kijak proposed that sexuality was a central part of being a human, and he discussed how it comprised of:

- the sexual act
- gender identities and roles,
- sexual orientation
- eroticism
- pleasure
- intimacy and reproduction

This perspective of an individual's sexuality has been proposed in other studies, for example in Southard & Keller's study (2009) of the importance of sex when professionals are assessing the impact of any disease upon an individual's sexuality. This study reinforced the wide variety of definitions that people possess concerning sexuality and how it is imperative that professionals must take these into consideration when helping with sexuality. However, the emphasis upon the more physical side of sexuality is one of the primary misconceptions that is held by society (NICHCY, 1992).

Alternative interpretations have expanded upon the behaviourally centred aspects of sexuality and have examined sexuality from a more holistic point of view. Such a view encompasses the social aspect of sexuality which identifies how humans can seek and enjoy the various facets of friendships and affection. This idea of sexuality being more than just physical in nature was expanded upon by Haffner (1990) who identified that sexuality encompassed sexual knowledge, belief systems based upon ethical, moral and spiritual components, as well as the more physical facets. Furthermore, Sheerin and McKenna (2000) in their review of the literature described sexuality as requiring certain attributes to be expressed:

- A conscious perception and acceptance of one's sexual identity at a given time;
- Communication of feelings, impulses and qualities associated with this sexual identity;
- Reception, interpretation and reciprocation of these feelings, impulses and qualities on the part of other(s);
- Context: gratification of self and/or others

Sheerin and McKenna, 2000, p9

Concerning the present thesis, sexuality will be seen as encompassing the wider concepts of emotions and social aspects of life. This, as discussed in the previous section, is an area which is frequently problematic for people with autistic spectrum condition and can lead to difficulties relating to the successful expression of their sexuality.

CHAPTER TWO

Sexuality in relation to Intellectual and Developmental Disabilities and Autistic Spectrum Condition

2.1 Intellectual Disabilities and Sexuality

2.1.1 Historical Background: Eugenics Movement

During the early part of the last century, the idea of people with intellectual and developmental disabilities having sexual feelings and so having the need to understand about sex was rare (Brown, 1994). Such attitudes were fuelled by the Eugenics movement which aimed for perfection within society and the need to ensure that any person perceived as possessing an imperfection did not add to the overall gene pool. The origins of the movement were based upon Charles Darwin and his "Origin of the Species" which discussed the survival of the fittest within species. This point of view was carried forward by social Darwinists who started to question the principle of caring for the "weaker" members of society, as to do so would enable the weaker to reproduce and survive when, they argued, they were not meant to (Brignell, 2010). By caring for such groups, the Eugenicists felt that it would undermine the natural order and thus cause degeneration in the human race. In his book, "The Descent of Man", Darwin wrote "We civilised.... do our utmost to check the process of elimination; we build asylums for the imbecile, the maimed and the sick. Thus, the weak members of society propagate their kind." (p168-169, Darwin, 1871)

Prior to the Second World War and Adolf Hitler's extreme views resulting in the holocaust, the Eugenics movement was strong within the United States and the UK. This Eugenics movement was further guided by Darwin's cousin, Francis Galton, who coined the 'eugenics' term as well as writing about a eugenics-based utopia (MacKenzie, 1975). At this point in history society viewed eugenics as a feasible possibility, especially as the professional middle class felt that selective breeding within their social class ensured that the resulting level of intelligence and mental ability was superior to the rest of society. This led to the belief that the "feeble-minded" should be discouraged from reproducing. As the years progressed, Royal Commissions were conducted on the care of a variety of disabled groups, such as the Royal Commission on the Care and Control of the Feeble-Minded

(Dickinson, 1909), reinforcing Galton's original ideas. Further validation of the eugenics view came in 1912 with the first International Eugenics Conference being held in London, with guests including Winston Churchill. In the 1930s the influence of the British Eugenics Society started to impact Parliament with a departmental Committee on Sterilisation recommending legislation regarding "involuntary sterilisation" of "mentally defective women" (Wright & Digby, 1996). As time progressed, the influence of the eugenics movement started to weaken with opposition from political parties (McNichol, 1989) and the weakening of the scientific aspects of the movement, particularly after the fall of fascism in the second world war. Such approaches toward the sterilisation of individuals with intellectual disabilities, however, particularly for women, were prevalent across the USA and several European countries. Even with the decline of the eugenics movement, such practises as involuntary sterilisation continued for years, supposedly on the grounds of social or therapeutic reasons (Dyer, 1987; Thomson, 1998). Such reasoning included the idea that by sterilising women with intellectual disabilities they would be liberated as they could live outside of institutions without the risk of pregnancy (Engwall, 2004) or the experience of menstruation (Martin, 1989). This latter issue was apparent in a number of referrals for sterilisation made in England and Wales between 1988 and 1999 (Stansfield et al, 2007).

In the USA and Canada, the legislation of compulsory sterilisation had been in place since 1907 when Indiana became the first US State to implement such legislation. The number of states and cases of sterilisation increased thereafter, with 13,000 US citizens being sterilised between 1946 and 1956 (Reilly, 1977). Similar legislation was passed in two Canadian States as well as several European countries, including Sweden, Austria, Norway, Iceland, Switzerland and Belgium (Park & Radford, 1998). Although much of the sterilisation was linked with institutional practices, which were on the decline with the move to the community in the 1970s and 1980s, some countries such as Belgium continue to advocate such practices (Servais et al, 2004). In certain circumstances, sterilisation became part of the conditions for women to leave the institutions and moving to community settings. For example, for Ingiborg Eide Geirsdóttir who was a 26 years old woman with intellectual disabilities, living in Iceland, as part of the "contract" for her moving into the community, she had to be sterilised or remain in the institution (Engwall, 2004).

2.1.2 Institutional Care and its impact

“A total institution may be defined as a place of residence and work where a large number of like-situated individuals, cut off from the wider society for an appreciable period of time, together lead an enclosed, formally administered round of life.” (p. xiii)

Goffman, 1961

The development of institutions for people with intellectual disabilities has been around since the Victorian era when asylums were built to house people with disabilities, including those who were seen as “idiots”, “feeble-minded” and “imbecilic” to name just three of the terms used to describe someone with intellectual and developmental disabilities. Prior to the development of asylums, or institutions, the care and support for such individuals centred upon the family, but with the arrival of the Industrial Revolution and the growing Eugenics Movement, attitudes towards the less able darkened. The need for all members of society to constructively contribute to the overall wellbeing of society, in general led to the care of the less able to make such a contribution being transferred to the isolation of the asylums, such as St Lawrence’s Hospital in Caterham and Earlswood Hospital in Redhill. When the institutions became overcrowded, then the “feeble-minded” were placed in workhouses along with individuals with mental health issues and those individuals whom society deemed as demonstrating deviant behaviour in some way. Consequently, many people with IDD ended up living with a range of social “misfits” including prostitutes and political activists, as well as “gutter children” who were often victims of sexual abuse. These individuals would be removed to the institutions to reduce damage or ‘contamination’ of others (Brown & Barrett, 2002). The introduction of the Mental Deficiency Act 1913 in the UK simplified the process involved in placing individuals into such institutions. With such legislation in place, the availability of places in institutions increased and the blueprint of large, isolated colonies housing a range of people became the norm (Wood Report, 1929) and did have some positive opportunities for people with intellectual and developmental disabilities. Often institutional life provided the individuals with long-term relationships and friendships (Deacon, 1974), as well as a level of independence to access a range of on-site facilities (e.g. farms, shops and entertainment). The move to a more community-based provision in the 1970s and 1980s, although positive, came with its problems. Often the move to the community provided an environmental change but not a “cultural” change, particularly regarding

being controlled by staff due to perceived 'risk' in accessing the community (Johnson & Traustadotter, 2000). Often the experiences and friendships gained within the larger institutions were dramatically reduced in the smaller community housing (Johnson & Traustadotter, 2000), although as time has passed so these situations have improved (Gates, 2004). Prior to the legislative and attitudinal change regarding the care and support of individuals with intellectual and developmental disabilities in the community, the colonies became "hospitals" following the 1946 NHS Act passing control of such institutions to the Minister of Health. Although the medicalization of institutions changed how they were perceived, it did not necessarily improve the lives of those within. Expression of sexuality and sexual abuse within the enclosure of institutional boundaries remained the same. Often the size of institutions meant that a single-sex offender, whether staff or resident, could gain access to a wide range and number of potential victims (Craft, 1994).

Life within an institution often involved the dehumanisation of individuals resulting in people with IDD losing the protection and dignity that every human being possesses (Wolfensberger, 1972). Such views of dehumanisation often provided justification for sexual offenders who felt that individuals with IDD could not feel pain and so could not be harmed (Sinason cited in Craft, 1994). Institutional life meant large shared dormitories and segregation of men and women, with only occasional controlled contact between the sexes occurring (Wright & Digby, 1996; Johnson & Traustadottir, 2000). The results of such dehumanisation and segregation reduced the ability for individuals to display appropriate sexual behaviour. This was further moulded by parental views at that time which showed great concern about the difficulties in sexual control of adolescent daughters. Such views potentially resulted in higher familial referrals for females than males to be placed within an institution (in 1922 the ratio was 201 women compared to 51 men and 1932 146 women compared to 25 men) (Wright & Digby, 1996). In the institutional environment, the ability for an individual to understand and effectively express their sexuality was limited. Even if sex education had been provided, the public nature of the living conditions meant that intimate relationships were difficult to perform in a suitably private way. Relationships apparently occurred amongst "patients" and staff alike, and were often abusive in nature or based upon misconceptions about what a sexual relationship entails, such as 'Jane King' who had a reputation for being promiscuous as she would have sex in exchange for cigarettes and alcohol (Johnson & Traustadottir, 2000). It is important to

note that for 'Jane King' was in no way an exception, and female residents in institutions having sex for money/cigarettes was the norm rather than the exception (McCarthy, 1999). Cases of physical abuse and neglect in institutions were finally exposed and investigated with the revelations exposed by various scandals, including in Ely Hospital in 1967 and Normansfield Hospital in 1978. Examples of sexual abuse were also explored, and prosecutions brought, although often sometime after the events, such as in the Longcare homes scandal (Hampshire Safeguarding Adults Board, 1998). At the same time, the developing concepts of normalisation and subsequent social role valorisation started a change in attitude about people with intellectual and developmental disabilities, especially following the abuse scandals highlighted at the hospitals. However, even within such 'revolutionary' changes in attitude, the issue of sexuality proved difficult to accept, often resulting in services trying to limit such 'rule-breaking' through desexualisation (Brown, 1994). This 'rule-breaking' often centred around what was and what was not perceived as "normal" by support staff and services, including whether people with intellectual and developmental disabilities should be engaging in sexual activity at all.

The publication of "Better Services for the Mentally Handicapped" (DHSS, 1971) provided the start of the move toward community-based care with many of its targets being met by the time "Valuing People: A New Strategy for Learning Disability for the 21st Century" (DHSS, 2001) was published. The latter provided further momentum for this change in care approaches and support. With the move to deinstitutionalise the patients and the closure of the large hospitals, the hope was for improved lives (Kinsella, 1993). The impact upon sexuality under deinstitutionalisation was a double-edged sword. On one side the rights of individuals with IDD were beginning to be recognised, including rights to sexuality. However on the flip side although it was hoped that the brave new world would enable people who had been institutionalised for decades to be safely integrated into the wider society, after living so long without the knowledge, appropriate experience and support, keeping "control" of a person's sexuality proved difficult for many individuals who moved from the large institutions. Unfortunately, as discussed within several studies (Katoda, 1993; Cuskelly & Bryde, 2004; Pownall et al, 2012; McConkey & Leavey, 2013) the process of deinstitutionalisation has not necessarily changed the underlying attitude toward the positive promotion of the sexuality of individuals with IDD. Within the move toward deinstitutionalisation and the implementation of

normalisation, there was recognition by some (Mulhern, 1975) that the difference between the values of normalisation and the attitude of residential staff resulted in a strain regarding sexual behaviour. Consequently, although the principle of deinstitutionalisation was positive and well-intended, it was based more upon environmental change occurring than in the attitudinal change of all involved. This did not include the development of individual skills including appropriate expression of sexuality in the new environments. This continued to place individuals in vulnerable positions and led them to be open to abuse but within a different environment. (This will be further discussed in a later section).

2.1.3 Policies and legislation associated with sexuality and IDD

As time has progressed, the topic of sexuality has been highlighted in a range of policies and legislation. In many cases, the reference is in generic terms, such as in the UK, Human Rights Act (1998) “every human being has a right to respect for private and family life (Article 8)”. This was expanded upon in later years with, for example, the UN Convention on the Rights of Persons with Disabilities (2006) within which it is asserted that people with disabilities are not to be discriminated against concerning marriage and relationships (Article 23), as well as being in receipt of good healthcare including sexual health (Article 25).

Concerning individuals with intellectual and developmental disabilities in the UK, various recommendations have been made through the years, although whether the long-term impact has been positive is debatable. In 2000, guidance on the teaching of sex and relationships for children with special educational needs and learning difficulties came in the form of the Department for Education and Skills SRE guidance (DfEE, 2000). This briefly outlined the duty of all schools; mainstream and special, to include pupils with additional needs in such programmes in order to help them understand their physical and emotional development to enable positive decision making. However, this was only guidance, and apart from a legal responsibility upon the part of school governors to ensure an SRE policy was in place and was accessible to all, the implementation of such programmes continued to be the responsibility of individual teachers and departments. In 2001, the UK government’s Valuing People White Paper (DofH, 2001) was introduced as a ground-breaking

policy in the arena of intellectual disabilities. Although the white paper aimed to promote and enhance the rights of people with intellectual and developmental disabilities to improve their quality of life, the mention of sexuality was limited primarily to a general statement concerning the need for services to help individuals with intellectual disabilities in forming relationships of all forms: -

“Good services will help people with learning disabilities develop opportunities to form relationships, including ones of a physical and sexual nature. It is important that people can receive accessible sex education and information about relationships and contraception”
(para 7.39, p81)

Nearly a decade later, the follow-up UK government paper Valuing People Now (2009) discussed more about the topic, but as with its predecessor, this discussion was broad in nature:

“...the importance of enabling people with learning disabilities to meet new people, form all kinds of relationships, and to lead a fulfilling life with access to a diverse range of social and leisure activities. It also emphasises their right to become parents and the need for adequate support to sustain the family unit.” (para 18, p.9)

Once again, the needs of people with intellectual and developmental disabilities concerning developing sexuality are seemingly recognised but no definite plans are put in place. The resulting turmoil leaves individual services attempting to develop approaches and programmes often on a crisis basis.

The legalities relating to people with intellectual and developmental disabilities and their sexuality has been complex and changeable over the years. Amongst the complexities has been the understanding of the possibility that an individual with IDD does not always possess sexual knowledge that is age-appropriate (McGillivray, 1992). Such lack of knowledge can be through the ability to retain learnt information (Aunos & Feldman, 2002), or through the inadequacies in the sex education being provided (McCabe, 1999) and subsequent relationship-based information.

2.1.4 Consent

Central to the legal aspects of sexuality is the capacity to consent. As discussed by Murphy and O'Callaghan (2004), in the UK, in the area of general decision-making and consent, for example concerning medical treatment, it is considered that a person has to be able to:

- Understand and retain information about the proposed treatment (its risks and benefits, as well as the alternatives and the risks and benefits of those alternatives);
- Weigh the information in the balance to make a decision;
- Communicate the decision.

Murphy & O'Callaghan, 2004

Many western countries have similar definitions of capacity which have developed over the decades as understanding about the issues connected with capacity to consent has increased (Grisso et al, 1998). The ability to consent can be fluid in nature, as an individual can lack the capacity to consent temporarily through physical or mental conditions that cause confusion, including alcohol and drug intoxications. This variation was highlighted by Lyden (2007) who identified capacity being a state which can vary over time. Lyden's elaboration of the issue of consent regarding individuals with intellectual and developmental disabilities having sexual relations demonstrated the need for repeated sexual consent capacity assessment. This is especially relevant when lack of capacity to consent has origins in a lack of knowledge which can, with appropriate support, be developed over time and thus improve the individual's capacity to consent.

The Mental Capacity Act (2005) in England and Wales (Adults with Incapacity Act (2000) for Scotland) provides the legal framework in relation to capacity to consent for individuals with intellectual and developmental disabilities. Amendments were made to the Act via the Mental Health Act (2007) following the European Court of Human Rights ruling regarding the "Bournewood" judgement, many of which centred upon the issue of consent and potential deprivation of liberty. The central consent elements of the Mental Capacity Act (2005) provide five core principles aimed at protecting the individual whilst also maximising their ability to make decisions:

- **Presumption of capacity** (section 1(2) MCA). Every adult has the right to make their own decisions if they have the capacity to do so. Family carers and healthcare or social care staff must assume that a person has the capacity to make decisions unless it can be established that the person does not have capacity
- **Maximising decision-making capacity** (section 1(3) MCA). People should receive support to help them make their own decisions. Before concluding that someone lacks capacity to make a particular decision, it is important to take all possible steps to try to help them reach a decision themselves.
- **Right to make unwise decisions** (section 1(4) MCA). People have the right to make decisions that others might think are unwise. A person who makes a decision that others think is unwise should not automatically be labelled as lacking the capacity to make a decision.
- **Best interests** (section 1(5) MCA). Any act done for, or any decision made on behalf of, someone who lacks capacity must be in their best interests.
- **Least restrictive option** (section 1(6) MCA). Any act done for, or any decision made on behalf of, someone who lacks capacity should be the least restrictive option possible.

Although the act provides a legal framework to clarify a number of uncertainties in relation to who makes decisions for those lacking capacity, the question of how to apply appropriate tests to the issue of capacity to engage in sexual acts still remains a difficult one for courts. The Mental Capacity Act specifically excludes decisions about sexual relationships from those that can be made by others, for example through best interest's meetings. Nevertheless, there have been several rulings about individual cases concerning consent to sex, for example as to whether the ability to consent to the sexual act refers only to the act with a specific individual (*Local Authority X v MM and KM (2007)*). In this case, the court considered that the woman, MM, was able to consent to sexual activity in general, but not able to consent in relation to the particular individuals she had sexual intercourse with. Further cases (*Local Authority v H*) explored the moral and emotional aspects of sexual relations, much of which was felt to be unmeasurable. In this particular case, Mr Justice Hedley made orders declaring that H's capacity in many areas, but particularly in regard to sexual relations, was

insufficient to give consent. However, Mr Justice Hedley's ruling was not against her ability to retain the information that is required to make such decisions but about her inability to utilise this information appropriately in order to have a sexual relationship. Such uncertainties are further compounded by Section 27 of the Mental Health Act which excludes decisions concerning family relationships (e.g. consent to marriage, sexual relationships, divorce, etc) from being made on behalf of an individual under best interest practice, although the individual's ability to consent must be assessed to ensure they are capable of making such decisions.

2.1.5 Sex Offences Act 2003

The Sexual Offences Act 2003 was an updated version of previous Acts some of which provided specific protection for individuals with intellectual disabilities (e.g. the Sexual Offences Act of 1956). The 2003 Act outlined issues relating to people with mental disorders, including those with intellectual disabilities, and provided them with some legal protection in relation to being taken advantage of by potential abusers. Concerning the underlying definition of consent, the Sexual Offences 2003 provided an alternative definition to that set out in the Mental Capacity Act. Where incapacity to choose was defined as a lack of sufficient understanding by the individual in relation to the nature of the act, or of the reasonably foreseeable consequences.

“A person consents if he/she agrees by choice and has the freedom and capacity to make that choice.”

The effect of the Act was to allow people with severe intellectual disabilities the right to consent to sex for themselves provided they had sufficient understanding of the nature of the act and its consequences. This was in stark contrast to the Sexual Offences Act 1956 which simply prohibited sexual relationships with those with severe intellectual disabilities.

Although the Act was designed to protect the general public from sexual crimes, concerning people who are vulnerable from abuse there are several additional sections which provide further protection. These are primarily:

- **Sections 30-33: Offences against person with a mental disorder impeding choice**

These sections concern sexual acts with or in the presence of someone with a mental disorder who is unable to consent to these acts.

- **Sections 34-37: Inducements, etc. to persons with a mental disorder**

These sections take the offences one step further by including the coercion of an individual with a mental disorder into partaking or witnessing a sexual act via an inducement (bribery), threat or deception by another individual.

- **Sections 28-44: Care workers for persons with a mental disorder**

These sections define what a care worker is, taking into account the issue of spouses/civil partners and putting in place the boundaries and limits concerning sexual activities with and in the presence of individuals with a mental disorder that they may be supporting.

Also, in the introduction of the 2003 Act, further protections were put into place to reflect the changing world, especially concerning the grooming of children via the internet. This is an important aspect for individuals with intellectual disabilities who access the internet.

2.2 Autistic Spectrum Condition and Sexuality

2.2.1 Adolescent development in teenagers with Autistic Spectrum Condition

When exploring the specifics of sexual development in relation to those with Autistic Spectrum Condition, it is reported that physically there are no significant differences from their mainstream counterparts (Murphy & Elias, 2006). However, in regards to the socio-sexual aspects of adolescent development when associated with autistic spectrum condition, “The growth of sexual drive, as a rule, is not accompanied by a corresponding growth in the field of social ‘know-how’, and this often

leads to embarrassing behaviour.” (Gilbert & Coleman, 1992). When attempting to explore the theoretical framework in regards to the development of individuals with autistic spectrum condition, the emphasis is very much upon how specific autistic spectrum condition related issues have an impact upon this area of development. Some of these issues have been discussed elsewhere in this thesis (Social difficulties Chapter 1; Scripting Chapter 2), other areas include communication difficulties as a significant number of individuals with autistic spectrum condition possess some form of communication difficulty (Tager-Flashberg, Paul & Lord, 2005). These difficulties include echolalia, voice intonation and delays in the comprehension of what is being said to the individual. Such difficulties can impact upon the ability of the individual with autistic spectrum condition to effectively explore some of the abstract issues linked with sexuality and relationships. This is especially true when considering how much communication involves subtle non- verbal methods. Also, there are issues relating to the limits involved for individuals with autistic spectrum condition being able to label and discuss sexual and developmental issues (e.g. terminology and making connections with for example pain of menstruation) (Gabriels & Van Bourgondien cited in Gabriels & Hill, 2007). As well as communication, some of the behaviour associated with autistic spectrum condition, such as obsessions, stereotypical and stimulatory behaviour, can impact upon the socio-sexual development of individuals with autistic spectrum condition. This is particularly true when the individual partakes in self-stimulatory activities such as masturbation which can be pleasurable on a sexual and sensory level, but which may become an obsession due to the ease of access (Gillberg & Coleman, 1992). This can also involve inappropriate usage of objects to aid the situation, but which are perceived by others as ‘strange’ or inappropriate (Van Bourgondien et al, 1997; Brown 2018). Also, the issue of obsessions can result in the display of inappropriate behaviour (e.g. following someone whom an individual has feelings for, but this could be seen as stalking) which could be perceived as potentially illegal but which might have no malicious intent by the individual with autistic spectrum condition.

2.2.2 Misconceptions

Whether an individual with Autistic Spectrum Condition wants, needs or is capable of developing their sexuality has been in dispute for many years and subsequent research has been seemingly limited (Tullis & Zangrillo, 2013). Due to the social difficulties that are part of the Triad of Impairment, for many years it was thought that individuals with Autistic Spectrum Condition shied away from such

urges and thoughts, and it was considered that the number of individuals with Autistic Spectrum Condition who were interested in such things as dating and sexual relationships was limited (Ousley & Mesibov, 1991). Often early research highlighted the negative aspects of Autistic Spectrum Condition and sexuality, such as a tendency to masturbate in public, self-harming in relation to masturbation and also their sexual behaviour toward others (Gillberg & Coleman, 1983). Also, there were difficulties relating to the methodology of many studies that have looked at this subject as they have tended to focus on the perspectives of parents and caregivers rather than the individual (Byers et al, 2013). Therefore, there seemed to be no need to develop programmes for such individuals. Or if such programmes were developed it was only due to difficulties that had occurred, often due to either socially deviant sexual behaviour (e.g. public masturbation) or situations involving abuse (Gerhardt & Lanier, 2011; Koller, 2000; Sullivan & Caterino, 2008). Such a reactive approach can be compared to developing a more skill-centred programme in order to decrease the occurrences of such incidents (Tullis & Zangrillo, 2013).

However, as time has progressed so has the realisation that, although some individuals do find difficulties in this area or do not want to participate in the social/sexual side of life, many still want what everybody else wants, including the ability to have a relationship, express and explore their sexuality (Henault & Attwood, 2002). More recent studies have countered some of the social stereotypes that have been built over the years. Byers et al (2013) study of the sexual wellbeing of adults with Autistic Spectrum Condition indicated the case was the opposite of that previously assured, with many participants being knowledgeable concerning sexuality and regularly engaging in appropriate sexual activities. Although these were positive outcomes, they did not provide any further information about the likelihood (or not) that individuals with Autistic Spectrum Condition will engage in inappropriate sexual behaviour, something that had been described in a series of case studies (Allen et al, 2008; Stokes et al, 2007; Woodbury-Smith et al, 2006).

2.2.3 Social Impairments and the effect upon sexuality

Being on the “autistic spectrum” can impact upon the degree of difficulties experienced by individuals. Several studies have indicated the difficulties confronted by adolescents with High Functioning Autism including:

- Poor social behaviours
- Poor understanding in relation to privacy
- Being in receipt of less education than their neuro-typical counterparts
- Displaying more inappropriate sexual behaviours.

Stokes & Kaur, 2005, p278

The overarching difficulty with social behaviour is one that is frequently associated with Autistic Spectrum Condition (DSM-IV, Howlin 2004). The impact of this impairment raises many issues, especially concerning the issue of sexuality as Ruble and Dalrymple (1993) commented:

- How individuals with Autistic Spectrum Condition learn about relationships and intimacy
- Understanding the relationship between behaviours and sexual development
- How much does teaching in relation to the topic of sexuality and intimacy reduce the difficulties experienced by individuals with Autistic Spectrum Condition.
- What are the differences between sexual behaviours and need-for-intimacy behaviours and how can they be distinguished?
- How much does gender role bias within parents influence the training and support for individuals with Autistic Spectrum Condition in relation to sexuality issues?

Ruble & Dalrymple, 1993, p239

As previously discussed within Chapter One, there are a number of areas associated with Autistic Spectrum Condition that impact upon an individual’s social skills. The basis of a healthy and happy relationship is understanding the various social factors, many of which are subtle and reliant upon individual interpretation, as well as an ability to understand and react appropriately to emotions. In

the absence of such skills and without appropriate training and support, many individuals with Autistic Spectrum Condition will fill the void using other sources. Often these sources may include their peers who may also have difficulties in these areas, accessing material (including pornography) online, etc. Such approaches can result in the individual taking a literal view and using this as a basis for their relationship development. The latter has provided further difficulties in relation to the issue of relationships as the use of technology ever increases (Tullis & Zangrillo, 2013), and the associated rules and regulations develop. Further confusion arises for the individual when being encouraged to utilise computer-based technology in order to develop various skills (Payne et al, 2012) and social skills (Sansosti & Powell-Smith, 2008). To some, this may place them in a quandary as they feel justified in accessing online sites as an extension of what they have been taught.

Further technological difficulties occur when individuals with Autistic Spectrum Condition are confronted with behaviours such as “Sexting” by other adolescents. “Sexting” involves the distribution of messages or images that are sexually explicit in nature via electronic devices (Houck, 2013). Although research into sexting and risks involved with sexual solicitation is limited (Normand & Sallafranque-St-Louis, 2015), and even more so concerning those with Autistic Spectrum Condition, the issue of sexting and its consequences have been highlighted in the popular press. Although all of these technological gateways into the world of sex and sexuality can aid an individual’s fantasy and imagination (McCarthy & Thompson, 2010) it is full of potential misinterpretations due to communication issues (Henault, 2006). Appropriate teaching and usage of technology are imperative when supporting individuals with Autistic Spectrum Condition, especially in the light of the permanency of online images which can result in further distribution of the evidence and subsequent risk of bullying, etc (Houck, 2013).

Within the autistic spectrum, obsessional behaviour can be frequently experienced by individuals and can frequently overflow into the world of sexuality. Obsession within this area can take many forms including accessing and excessively using pornographic materials, compulsive sexual behaviours such as masturbation and the excessive need to obtain sexual contact and closeness (Henault, 2006). In attempting to satisfy such obsessions, often an individual will do so without any concern for either

the consequences of their actions or the individual involved (Barry-Walsh & Mullen, 2004; Allen et al, 2008). Such impairments in social skills, along with unclear boundaries within society between appropriate and inappropriate relationship boundaries (Stokes et al, 2007), can often place an individual with Autistic Spectrum Condition in a potentially law-breaking position. Evidence has demonstrated how such individuals will seek contact from others (Clements & Zarkowski, 2000; Myles & Simpson, 2002) which can become intense in nature, e.g. stalking and harassment, and in so doing the individual can also become vulnerable concerning recognising the intention of others:

“My over-attachment problems with friends at school and at church meant that others were quickly wary of me or used me to their own ends. I did not recognise the signs that might have alerted me to the ‘abusive potential’ of some individuals, nor could I separate out the probability of a likely ‘good’ person to relate to. My gullibility was apparent to all, and this made me very vulnerable.”

Lawson, 2005 (p.129-130)

Concerning the sexual vulnerability of individuals with autistic spectrum condition, there are several areas in which the individual may have difficulties. One of the underlying aspects of the condition centres upon a person’s ability to learn about and understand the unwritten rules that are followed throughout our daily lives. These “scripts” (Wiederman, 2005) inform us about how we should behave within social situations, including areas such as the unwritten rules relating to urinal etiquette for men which is a set of unwritten rules followed but never openly taught to boys (See Fig. 4). Unfortunately, these scripts are not necessarily written down and are also meant as general guidance from which people work, as opposed to fixed rules (Dukes & McGuire, 2009). Although the idea of scripts may initially seem beneficial for someone with autistic spectrum condition who have a preference for structure, unfortunately, such scripts are not necessarily written down, formally taught or consistent in their implementation.

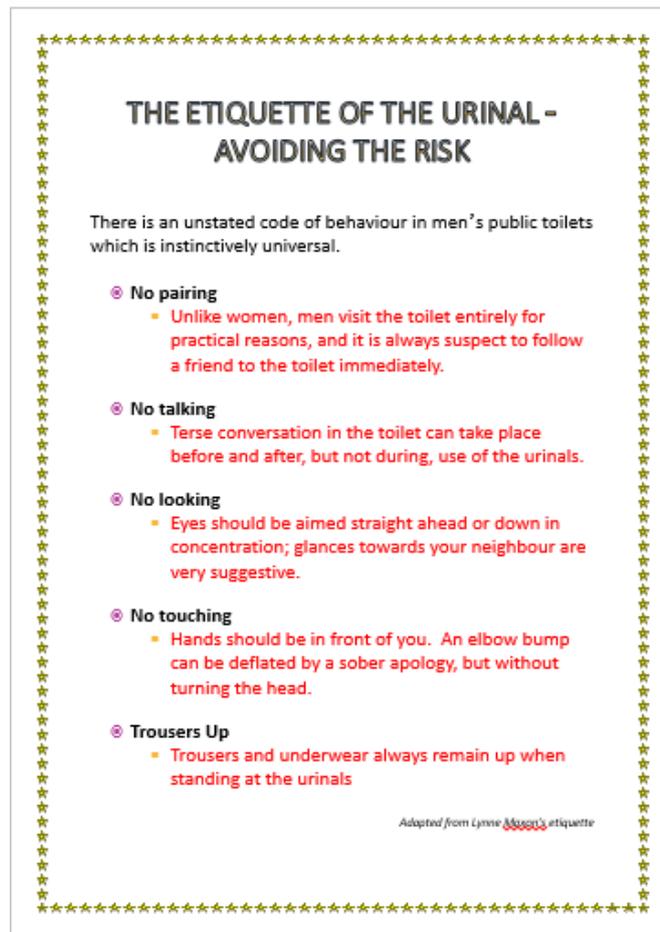


Fig 2.1. – Urinal Etiquette adapted from Lynne Moxon's etiquette (Moxon, 2016)

Instead, the scripts are often learnt through osmosis along with some guidance from those around. Subsequently, it is left to the individual to work through each script which changes with every situation and person involved. As has been highlighted, the acquisition of such subtle knowledge can be problematic for individuals with autistic spectrum condition. The result can be that an individual follows scripts inappropriately, misses out or misjudges steps, and so become involved with the Criminal Justice System. Such consequences demonstrate how there is a need to provide such understanding in the individual, but which is not often considered within present sex education programmes.

As well as scripting, it is known that being able to recognise the intention of others can be problematic for someone with autistic spectrum condition due to the need to be able to read and understand non-verbal cues. The ability to have some insight into the intentions of others impacts upon the possibility of being coerced into activities that may not be appropriate or legal. Often the lack of such skills, especially in someone with autistic spectrum condition, can place them in a position within which their “innocence” and underlying feelings lay them open to suggestions, e.g. being persuaded to text an explicit picture to someone underage. In conjunction with this can be the general lack of knowledge surrounding sex and sexuality such as the legal framework relating to consent which, although part of the SRE programme, can often only be superficially explored due to limited time and resources which are not necessarily conducive to someone with autistic spectrum condition. Such individuals may require further clarification about the situation in comparison to their neurotypical counterparts. Additionally, such social naiveté can cause difficulties in relation to the misinterpretation of what is needed to develop relationships (Murrie et al, 2002). In the wider context, Murrie et al also illustrated how a lack of insight into the appropriateness of the consequences can have disastrous results, especially regarding a lack of insight into the maintenance of a sexually inappropriate relationship. For example, one case utilised within the study highlighted how one 27-year-old male’s courtship strategies involved harassing a specific woman by being around her until he could “persuade” her to have sex with him. However, this often resulted in the male being exploited by those around him, whether sex occurred or not. This exploitation often involved illegal activities, including drug dealing. Such examples are not uncommon and can often result in contact with the Criminal Justice System.

Difficulties surrounding privacy, including undressing in public and touching private parts in public, have also been seen as problematic for some individuals with Autistic Spectrum Condition. Research has indicated that such behaviours require more explicit teaching of rules and boundaries, particularly for those classed as High Functioning Autism (who may be out alone), to reduce the likelihood of such issues (Ruble & Dalrymple, 1993; Stokes & Kaur, 2005). However even when such education is provided, the chance of such problems occurring was still significantly more likely than amongst their neuro-typical counterparts (Ruble & Dalrymple, 1993).

Overall the issues highlighted provide some evidence for the need to have sex education programmes designed for individuals with Autistic Spectrum Condition, much of which is centred upon the social aspect of sexuality rather than just about development and sexual intercourse. In so doing it can enhance the individual's overall quality of life (Konstantareous & Lunsky, 1998).

2.2.4 Gender Identity and Autistic Spectrum Condition

One area of sexuality development within individuals with autistic spectrum condition that has been explored in greater detail is that of gender identity. In recent times, it has been reported by gender identity services that there has been an increase in gender-related issues in regards to those with Autistic Spectrum Condition (Lehman & Leavy, 2016). With discussions occurring within the general media about the topic increasing and expanding into the realms of non-binary identity (Taylor et al, 2018) and the increasing options of gender identification available (Facebook offers 50 options in regards to gender identification according to Lehman & Leavy, (2016), it has been recognised that how an individual perceives their gender and feelings does not necessarily fit the binary labels that have previously been allocated (European Union Agency for Fundamental Rights, 2014).

Gender Identity Disorder (GID), or Gender Dysphoria (GD) relates to a strong sense of discomfort and distress relating to an individual's biologically assigned gender. This occurs alongside a persistent association with the opposite gender. The impact of gender dysphoria upon the individual can include discomfort/hatred toward gender-specific body parts, as well as the societal pressure to conform to the dress and behaviour of the individual's specific birth gender. As a consequence, the traditional genetic view of males and females has been replaced by a more fluid interpretation of gender (Sheppard & Mayo, 2013) which has cultural variations. Within the UK, the Gender Recognition Act (2004) was introduced providing transsexual people with the opportunity to be legally recognised as the gender with which they identify. Presently, this process involves the individual:

- Living as their preferred gender for two years,
- being diagnosed with gender dysphoria by two doctors.

However, recently in 2018, a change to this was proposed which would simplify the process by enabling trans people, including 16-17-year-olds, to self-identify as their preferred gender (without the diagnosis). This change would not only simplify the process but would also enable those individuals who identify as non-binary to self-identify which they cannot presently do.

Although it has been theorised that there is a relationship between GD and autistic spectrum condition (Janssen et al, 2016; Glidden et al, 2016; de Vries et al, 2010; Pasterski et al, 2014) much of the research has utilised limited data and case studies (Glidden et al, 2016). However, there are indications that the conditions can co-occur with each other. Studies have indicated that such co-occurrence has a higher rate than the occurrence of GD in the mainstream population. One study in Europe identified rates which were considerably higher than the general population when exploring the presentation of autistic spectrum condition in people attending a specialist gender clinic (7.8% reported with autistic spectrum condition compared to up to 1.16% in the general population, according to Vries et al (2010). In addition to providing prevalence rates, the study discussed how individuals with autistic spectrum condition received a separate diagnosis of Gender Identity Disorder Non-Specific (GID-NOS). This resulted from the clinician's view that the individual often misinterpreted the feeling of being different from their peers as being more about gender dysphoria rather than a social issue. Additionally, when exploring some of the physical more feminine aspects of boys with autistic spectrum condition and GD, the researchers highlighted how issues such as soft skin and hair, could potentially be more sensory-based than gender-related. One important aspect highlighted by Vries et al which has the potential to impact upon support methods relates to sexual attraction. Previous studies (Smith et al, 2005) have identified how individuals with GID but without autistic spectrum condition are generally attracted to people of their birth sex. In contrast, Vries et al results indicated the opposite for individuals with autistic spectrum condition. Although the latter study highlighted this aspect as being clinically significant in regards to lower postoperative satisfaction in those adult transsexuals who were not attracted to birth-sex individuals, it did not explore any autistic spectrum condition specific aspects. This is important in the support of those individuals with autistic spectrum condition and GID as it could potentially be an indication that such individuals may have misinterpreted their same sex attraction for GID. This raises potential concern regarding the proposed changes to the Gender Recognition Act. The ease with which an individual

with autistic spectrum condition will be able to self-identify without appropriate support and counselling could result in an increase in misidentification due to the perceptual/sensory aspects of autistic spectrum condition.

A further study exploring the presence of GD within a group of North American children with autistic spectrum condition found 5.4% of participants expressed a wish to be the opposite sex (Strang et al, 2014). Similar levels (5.1%) were also discovered in a later American based study exploring a similar group (Jansen et al, 2016). Additionally, the Jansen et al study also explored whether the change from child to adolescent had an impact upon an individual's perception of gender identity. The results indicated that age had no impact on the situation.

The issues raised have led to a discussion concerning potential causes for the links between autistic spectrum condition and GID. Central to this are the difficulties faced by individuals with autistic spectrum condition on both a general identity and social level. The previously mentioned study by Vries et al (2010) highlights the importance of the individual's developing identity. In relation to GD, there is a need to explore the underlying feelings concerning GD to ascertain whether such feelings are truly GD related or more social skills and identity development issues. Emotional aspects have also been discussed by others (Glidden et al, 2016) with regard to how individuals with autistic spectrum condition have some impairments in empathy and response to other's emotions. Consequently, it is theorised that such a lack of emotional understanding leads to individuals with autistic spectrum condition being more willing to 'come out' and pursue their wish to transition without any thoughts or consideration of societal beliefs or prejudice. Other factors include aspects such as the 'male brain' theory which results in above-average analytical brain, but a decreased level of empathy (Baron-Cohen et al, 2014). Issues relating to early relationship difficulties between child and mother have also been explored as possible causes of GD (Fonagy & Target, 2002), suggesting difficulties in forming such attachments resulting in specific genes not being activated. Regardless of the potential causes, the research that has taken place regarding the issue highlights the importance of ensuring that appropriate support is provided to ensure that any final decisions about GID have been thoroughly explored appropriately.

2.3 Sexual Abuse and People with IDD or Autistic Spectrum Condition

Research has highlighted the issue of abuse concerning individuals with intellectual disabilities (McCarthy & Thompson, 1997; Balogh et al, 2001). This has been reinforced by several abuse and mistreatment scandals relating to people with intellectual disabilities, as previously highlighted in this chapter. However, such scandals continue, including the Winterbourne View Hospital case in 2011 and most recently Whorlton Hall case in 2019². The latter two were revealed following undercover filming by the BBC 'Panorama' programme which resulted in 11 staff members working at Winterbourne View Hospital admitting to a total of 38 charges of ill-treatment of patients, many of whom were known to have autism, within the establishment. The resulting investigations resulted in widespread reviews of residential services across the country. The issue of abuse is not exclusively linked to residential services, of course, and the need to understand the issues in relation to people with intellectual disabilities, including those with autistic spectrum condition, is imperative if they are to be safe, especially concerning sexual abuse.

2.3.1 Definition of Abuse

“Abuse is a violation of an individual’s human and civil rights by any other person or persons.”

No Secrets, DH, 2000 (p9)

The definition of abuse covers a range of aspects, some of which have developed with the growth of technology and social media; however, the general consensus identifies the following forms:

- **physical abuse**, including hitting, slapping, pushing, kicking, misuse of medication, restraint, or inappropriate sanctions;
- **sexual abuse**, including rape and sexual assault or sexual acts to which the vulnerable adult has not consented, or could not consent or was pressured into consenting;

² At the time of writing this thesis, the Whorlton Hall case is still under investigation and so no recommendations or prosecutions have been made.

- **psychological abuse**, including emotional abuse, threats of harm or abandonment, deprivation of contact, humiliation, blaming, controlling, intimidation, coercion, harassment, verbal abuse, isolation or withdrawal from services or supportive networks;
- **financial or material abuse**, including theft, fraud, exploitation, pressure in connection with wills, property or inheritance or financial transactions, or the misuse or misappropriation of property, possessions or benefits;
- **neglect and acts of omission**, including ignoring medical or physical care needs, failure to provide access to appropriate health, social care or educational services, the withholding of the necessities of life, such as medication, adequate nutrition and heating; and
- **discriminatory abuse**, including racist, sexist, based on a person's disability, and other forms of harassment, slurs or similar treatment.

The legalities relating to sexual abuse have been previously discussed within this thesis (see section 2.1.5) including the central issue of consent. Sexual abuse occurs when any form of sexual interaction is forced upon a non-consenting individual, whether through legal reasons (e.g. incapacity) or by them saying "No", then the nature of the interaction becomes abusive (Barbaree & Marshall, 2006). The term sexual abuse covers several different sexual behaviours and situations:

- **A completed sex act** is defined as contact between the penis and the vulva or the penis and the anus involving penetration, however slight; contact between the mouth and penis, vulva, or anus; or penetration of the anal or genital opening of another person by a hand, finger, or other objects.
- **An attempted (but not completed) sex act** is defined as an individual having the intent to commit a sexual act and takes steps to achieve this goal but has been prevented from completing the act for some reason.
- **Abusive sexual contact** is defined as intentional touching, either directly or through the clothing, of the genitalia, anus, groin, breast, inner thigh, or buttocks of any person without his or her consent, or of a person who is unable to consent or refuse.

- **Non-contact sexual abuse** does not include physical contact of a sexual nature between the perpetrator and the victim. It includes acts such as voyeurism; intentional exposure of an individual to exhibitionism; unwanted exposure to pornography; verbal or behavioral sexual harassment; threats of sexual violence to accomplish some other end; or taking nude photographs of a sexual nature of another person without his or her consent or knowledge, or of a person who is unable to consent or refuse.

Sexual Offences Act, 2003

The latter category of non-contact sexual abuse incorporates more of the technological aspects that arise via the use of social media and webcams. This aspect of the definition can be the most problematic for those with autistic spectrum condition as many of the types of non-contact sexual abuse are reliant upon a fine balance between what can be perceived as socially acceptable and what is illegal. For example, an individual who likes another person may send frequent messages and communications to the other believing this to be fine when it could be interpreted as harassment by the recipient.

2.3.2. The occurrence of abuse with people with intellectual and developmental disabilities and autistic spectrum condition

As previously mentioned, the abuse of individuals, especially sexual abuse, has been present throughout institutional times. Several studies have identified the increased risk of abuse in those with physical disabilities (Horner-Johnson & Drum, 2006), with further increased risk in those with intellectual disabilities (Levy & Packman, 2004). A review of eighteen studies (Horner-Johnson & Drum, 2006) explored a range of disabilities with an emphasis on intellectual disabilities and Autistic Spectrum Condition. The prevalence rate identified within this review ranged from 11.5 to 28% of individuals who were sexually abused accounting for approximately half of the abuse of all kinds recorded within the studies. This review illustrated how individuals with intellectual disabilities were at more significant risk of abuse compared to those without intellectual disabilities. However, the

difficulties in the reporting of such incidents by victims with intellectual disabilities make it difficult to fully ascertain the true figures (Westcott & Jones, 1999), although even when cases of abuse are reported by staff the levels are still considerably higher than rates for other populations (Sobsey, 1994; Brown & Stein, 1998). Further research concerning children with intellectual and developmental disabilities (Cooke, 2000) illustrated issues relating to service difficulties and the various environments that such individuals experience resulting in the increased likelihood of an individual being abused, including individuals with Autistic Spectrum Condition. These environments, in turn, can allow greater access for sexual predators (Sevlever et al, 2013), especially in situations involving the need for intimate care (Edelson, 2010). Concerning actual prevalence rates for people with intellectual disabilities, a review of studies by Mandell et al (2005) showed estimates of between 40 to 60% of hospitalised children with developmental and multiple disabilities possessing a history of abuse. The high levels identified in comparison to the other studies may have been due to procedures within the hospital setting being more stringent than community settings and/or because hospitals are easy places to abuse children.

When turning attention to those with Autistic Spectrum Condition, statistics are limited due to only a few studies being available (Sevlever et al, 2013). Regardless of this lack of data, there has been an awareness surrounding the issue of sexual abuse and individuals with Autistic Spectrum Condition for a number of years. However often this has been more based upon the extrapolation of the figures concerning the empirical evidence relating to individuals with intellectual disabilities and the known population of individuals with Autistic Spectrum Condition within this group. On the one occasion that a study into the prevalence of sexual abuse within the Autistic Spectrum Condition population specifically has been performed (Mandell et al, 2005), the data was primarily based upon parental reporting. Although the use of such information sources is important, the study recognised that there were some difficulties concerning the topic, including the stigma surrounding sexual abuse and the probability that there had been many occasions that parents were unaware about. Additionally, the age of participants (primarily children) meant that there were limitations in being able to apply the results to the wider Autistic Spectrum Condition population, especially in relation to adults and those with experience of institutional care. However, the overall results of the study indicated that 1 in 6 of the participants had been victims of sexual abuse at some point. This figure is not much more than

those relating to the general population and intellectual disabilities, however, it is still significant especially when considering the potential shortfall due to the reporting difficulties previously discussed.

In addition to the statistical results, Mandell et al's study also highlighted the importance for people to recognise the behavioural results of being sexually abused. Unfortunately, this once again relied primarily on studies of individuals with intellectual disabilities rather than Autistic Spectrum Condition (Edelson & Joa, 2010). However, the interpretation of behavioural markers can be difficult due to the various types of behaviours that are often present in individuals with Autistic Spectrum Condition. Many of these behaviours can be indicators that the individual is having difficulties coping with life (e.g. increased self-stimulatory behaviour) (O'Callaghan & Murphy, 2003; Cunningham & Schreibman, 2008), but this could also be due to them being victims of sexual abuse. Other prominent behavioural issues related to the presence of sexualised behaviour, which some have suggested is more frequent in those who have been sexually abused (Bow, Quinnell, Zaroff & Assemany, 2002). However, such behaviour has been found to have occurred in response to physical abuse as well (Merrick et al, 2008).

“I am frightened to be put into a situation where I have to explain anything to anyone....Most of the time I just keep it to myself because I just make too many enemies when I say something....I am not really interested in anything anymore (although I once had the remarkable ability to be interested in anything). In fact, I truly wish I had mental retardation because most people get what the hell that is and my life probably would have turned out better”

(Prince-Hughes, 2002; p77-78)

The above quote comes from an adult with High Functioning Autism who expresses both the frustration linked with people not understanding her autism and also the despair that she holds following childhood abuse, including sexual, that she experienced. It is for individuals like her who work within the area of sexuality and sexual abuse are sorely needed to prevent such abuse and improve the understanding of neurotypical others.

Despite the lack of clarity in relation to the prevalence of sexual abuse in those with Autistic Spectrum Condition, it is recognised that it occurs and there are implications for the support services that are involved with such individuals (Mandell et al, 2005). This is especially true when various studies indicate that the negative implications of abuse are the same for children with disabilities as any other child (Mansel, Sobsey & Moskal, 1998; Sequeira & Hollins, 2003).

2.4 Conclusion

The aim of this chapter has been to explore some of the many sexuality issues that have been present through the years for individuals with intellectual disabilities, Autistic Spectrum Condition. Although society seems to have made massive steps forward in recognising the needs of these individuals, as demonstrated by the initial literature review there are still difficulties concerning skills deficits and how to reduce the vulnerability of individuals with intellectual disabilities, especially those with Autistic Spectrum Condition. This latter group has been shown within this chapter to possess a range of social skills deficits which potentially places them at greater risk, both to being abused and being an abuser, which require focus. The impact of abuse upon the individual can frequently be life-changing and yet too often individuals with intellectual disabilities, Autistic Spectrum Condition are ignored, or the situation underplayed, but the effects are still the same.

It seems that whatever the prevalence rates are for abuse of individuals with Autistic Spectrum Condition, something that in itself requires further study, education and skill development is a key component in relation to the individual's sexuality. This education is not just for the individual, but also for those who support people with Autistic Spectrum Condition. Although sex education occurs within schools and with individuals with Autistic Spectrum Condition, is it effective enough to ensure that such deficits are dealt with? This question will serve as the basis for the next chapter and both Study One and Study Two.

Chapter 3.

Sex Education, Intellectual Disability and Autistic Spectrum Condition

The development of an individual's sexuality is not only about their physical and sexual changes, but also about beliefs, values and sexual knowledge. Consequently, there are a number of factors influencing such development, including:

- The person's age, (Friedrich et al, 1998; Hornor, 2004)
- What is observed by the individual in the world around them (Friedrich et al, 1991)
- What and how the child is taught (NCTSN, 2009)

In most Western societies, although such development involves parents and school, frequently it is the school sex education programme that is central to the process. However, even in the mainstream sector, such programmes are reported as not being consistently effective in helping with the individual's development and understanding of their sexuality (Kirby, 2002). In considering those with intellectual and developmental disabilities and/or autistic spectrum condition, there are potentially further difficulties in implementation and attitudes about the provision of sex education programmes. The development of SRE programmes in general has been achieved over a century's worth of understanding and changing attitudes. In comparison, for individuals with intellectual and developmental disabilities and/or autistic spectrum condition programme development has only occurred since the 1970s.

Before utilising a systematic literature review to explore issues in the implementation of SRE programmes with individuals with intellectual and developmental disabilities and/or autistic spectrum condition, this chapter will provide a background to SRE. This will involve exploring the theoretical and historical context of SRE development in general. Attention will then be focussed upon how development has occurred in such programmes for individuals with intellectual and developmental disabilities and/or autistic spectrum condition. Finally, the systematic literature review will provide a more specific view of the evidence and issues regarding SRE programmes for individuals with autistic spectrum condition.

3.1 Health Promotion

The health of the public is central to the present UK health system, and sex education is part of this. However, over the years, the emphasis upon service delivery has needed to change as lifestyles have changed, as well as there being changes needed as a result of a growing amount of evidence about people's health (Wright, 1998). Additionally, as financial constraints affect all areas of society, the need for improved public health as a preventative measure increases. Unfortunately, within society the perceptions of health needs can vary depending upon who has recognised the need, their ability to resolve the need and the resources available to meet the need. In attempting to be proactive and meet the needs, the use of health promotion campaigns has often been reliant upon behaviour change occurring within the recipients (Kaplan, 1990; Salovey et al, 1998; Sherman et al, 2000). Attempts to make such changes are frequently linked with increasing the recipients' perception and understanding of the inherent risks involved with the "risky behaviour" that they are participating in (Sherman et al, 2000), in order to motivate the change to occur. However, such motivation can be reliant upon how an individual wants to interpret the information they have been given and/or whether their level of acceptance allows for the information (Ditto & Lopez, 1992; Weinstein & Klein, 1995), especially if the 'reward' from the health promotion does not fit with the individual's wishes (Morris & Swann, 1996). The achievement of such changes has resulted in the development of numerous general theories of health changing processes, including the Health Belief Model, Theory of Reasoned Action, and Theory of Planned Behaviour.

3.1.1 Health Belief Model

During the 1950's, the need for a conceptual framework in regard to changing and maintaining health related behaviours was clear (Connor & Norman, 1996). Central to this was the need to overcome the difficulties regarding why the public at the time would not participate in widespread disease prevention and detection programmes (Rosenstock, 1960). Consequently, the Health Belief Model was developed based upon the Stimulus Response (S-R) Theory (Watson, 1925) and Cognitive Theory (Lewin, 1951). The amalgamation of these two theories resulted in value-expectancy concepts which considered that individuals valued avoiding illness, by expecting that certain health actions will prevent such illness (Champion & Skinner, 2008).

The original concept focussed primarily upon preventative methods, but further development of the model later incorporated the identification of the use of health services and people’s compliance with medical approaches (Becker et al, 1977). Within the Health Belief Model, this was conceptualised using several keys areas which would guide how the model was utilised (See Table 3.1)

Concept	Definition	Application
Perceived susceptibility	Belief about the chances of experiencing a risk or getting a condition or disease	Define population(s) at risk, risk levels Personalize risk based on a person’s characteristics or behaviour Make perceived susceptibility more consistent with individual’s actual risk
Perceived severity	Belief about how serious a condition and its sequelae are	Specify consequences of risks and conditions
Perceived benefits	Belief in efficacy of the advised action to reduce risk or seriousness of impact	Define action to take how, where, when; clarify the positive effects to be expected
Perceived barriers	Belief about the tangible and psychological costs of the advised action	Identify and reduce perceived barriers through reassurance, correction of misinformation, incentives, assistance
Cues to action	Strategies to activate “readiness”	Provide how-to information, promote awareness, use appropriate reminder systems
Self-efficacy	Confidence in one’s ability to take action	Provide training and guidance in performing recommended action Use progressive goal setting Give verbal reinforcement Demonstrate desired behaviours Reduce anxiety

Table 3.1 - Key Concepts and Definitions of the Health Belief Model. (Glanz et al, 2008)

In relation to the effectiveness of the Health Belief Model, although it is seen that the model has provided a useful framework, there can be issues relating to situations when there are other factors present that may influence health behaviour, such as cultural beliefs, socioeconomic status or

perception of need. An example of such difficulties relates to the issue of risky sexual behaviour. Primarily the use of Health Belief Model has centred upon improving HIV prevention. In some studies, the aspect of perceived susceptibility to becoming HIV-positive has been a low motivator to behaviour change (Hounton et al, 2005), although in some studies this maybe more to do with varied measurements used (Ronis, 1992). Where the Health Belief Model has been found to be effective, this has often focussed upon skill training (self-efficacy), particularly the use of condoms, which some feel is needed due to other influences such as peer or negative social influences (Siegel et al, 2001).

3.1.2 Theory of Reasoned Action (TRA) and Theory of Planned Behaviour (TPB)

Both of these theories are based upon the concept that an individual chooses to make changes in their behaviour based upon the information provided to them and how they perceive the content of such information. Originally developed by Fishbein and Ajzen (1975), it utilised earlier work performed by Fishbein in relation to how attitudes may have an impact upon behaviour. The Theory of Planned Behaviour further developed the approach of the Theory of Reasoned Action by adding an extra dimension relating to an individual's ability to control the behaviour that has developed.

Both theories incorporate a number of psychological variables which impact upon an individual's behaviour for change to occur. These variables are:

- a) Intention
- b) Attitude toward the behaviour
- c) Subjective norm
- d) Perceived behavioural control
- e) Behavioural, normative and control beliefs

Fishbein et al, 1992, p292-296

The Theory of Planned Behaviour aspect further develops the Theory of Reasoned Action theory by incorporating an additional element to the predictor of intentions; the perceived behavioural control. This involves whether the individual perceives the performance of their behaviour as being easy or difficult.

A review by Noar and Zimmerman (2005) found that many of the theories used in relation to health promotion, and which come under the umbrella term of social cognition, possess strengths and support in their usage, but the issue of personal relevance is imperative in order to reduce defensiveness against the ideas whilst increasing acceptance of the health message (Sherman et al, 2000). In relation to the present issue of developing the understanding of individuals with autistic spectrum condition, especially concerning understanding sexuality and relationships, consideration of the theoretical basis illustrates how Theory of Reasoned Action and Planned Behaviour is more relevant than the Health Belief Model. Although the latter is a good approach, it is reliant upon external control mechanisms in order to achieve the end goal of good health. In contrast, individuals with Autistic Spectrum Condition will often make decisions about their situation based upon specific, logical information. Such information provides a foundation from which the individual can develop their thought process toward the decision, although this can be affected by how the individual perceives the information initially provided. Although this is not an incorrect perspective, often the approach provided within the Health Belief Model relating to providing guidance and information regarding the situation does not fit in to the frequently logical thought process involved with someone who has Autistic Spectrum Condition. The approach adopted with the alternative model of TRA/TPB takes into account several variables, including attitude, interpretation of the situation, and behavioural control aspects, which could enable an individual to further explore the situation. By providing the information in such a way, via TRA/TPB, there is more opportunity for an individual to further explore the situation from their own perspective in order to completely understand the situation. In comparison, Health Belief Model tends to be about informing someone what to do from the information provided regardless of how the individual may perceive the world around them. Regarding sex education, in this author's experience there is frequently a need for the individual with autistic spectrum condition to explore a situation taking into account their logical thought process as part of their processing methodology, something that TRA/TPB provides allowances for.

3.2 Sex Education – Programme Development

The attitudes around the topic of sex and sex education are often contradictory in Western culture. On one side stands the hushed attitude of not discussing such topics to prevent the corruption of our children's minds until they are truly adults and so capable of understanding such concepts. This

construct of “pre-sexual personhood” (Jackson, 1982; James & Prout, 1990) has led to cultural perceptions of children being non-sexual hindering the ability to discuss sex education (Alldred & David, 2007). In contrast is the ongoing sexualisation of children through the media, pop culture and fashion, which titillates rather than educates about sex. This contrast has continued throughout the latter part of the 20th Century including the development of sex education programmes, with views ranging from sex being a basic human right to it being a corruption of children’s innocence (Monk, 2000; Osler, 2005). Such a “protectionist” approach can prevent children accessing good, quality sex and relationships education. For the majority, foundation level sex education may not have been comprehensive enough, especially regarding the socio-sexual aspects. However, when good quality teaching of the subject occurs, it has been within a framework that attempts to encourage healthy and safe relationships, which has been shown to delay the onset of sexual activity in youngsters rather than encourage it (Blake & Jolly, 2002). These contrasting views are not solely based within the UK but are worldwide and often associated with difficulties involved in talking publicly about private matters (Epstein & Johnson, 1998). In the US this has resulted in two different curricula being developed: Comprehensive Sex Education and Abstinence-only. Political support for both resulted in governmental investment across the country with 30 states legislating for and implementing Abstinence-only programmes within their schools (Stranger-Hall & Hall, 2011). Research has shown that both programmes have a positive impact in delaying the onset of participants’ first sexual experience, but the Comprehensive Sex Education approach is more likely to encourage the appropriate use of contraceptive methods such as condoms, than does the Abstinence-only programme (Kohler et al, 2008).

In relation to the rest of the world, the level of political debate as well as moral, religious and cultural differences have had, and continue to have, an impact upon the implementation of sex education programmes. A study by Katoda (1993) comparing two such differing cultures; Sweden and Japan, demonstrated the impact of such differences upon the implementation of sex education. The study highlighted how parents in Sweden were more positive than those in Japan towards issues relating to sex and interpersonal relationships of young people generally. Such differences frequently occur across countries (Lewis & Knijn, 2002) and between regions within individual countries (McConkey & Leavey, 2013). However, even with such differences, a review of 83 studies relating to sex education

programmes across the globe including the USA, developed countries such as Norway, Spain and the UK, and developing countries including Belize, Chile and South Africa, highlighted similarities within programmes, including content and implementation (Kirby et al, 2007).

3.2.1 The Development of Sex Education within the UK

Within the UK, a formal sex education programme has only been integrated into the National Curriculum during the past few decades with the Education Act 1996, and subsequent legislation, outlining key areas for the implementation of Sex and Relationship Education (SRE) across England. Prior to this, sex education has varied depending upon the social policy and social pressures present at the time.

A review of the literature highlights how initially sex education programmes developed within the late nineteenth and early twentieth centuries. At this time the emphasis was with secondary aged pupils centred purely on general hygiene issues, especially for girls, considered at the time as an effective way to improve the nation's physical, sexual and moral health (Mort, 1987; Weeks, 1986). This had been part of the curriculum since 1870, however with the support of various publications, the additional element of "sex hygiene" (or sexual health teaching as it is now known) (Pilcher, 2004) was introduced by the new School Medical Service in 1908. However, such discussion about sex and its inclusion in the school programme caused controversy throughout the country (Pilcher, 2004).

The onset of World War One provided new motivation for a rethink as to the importance and relevance of teaching sex education within schools. Although at the time of World War One, there had been some encouragement by government agencies (Hall, 2004) for parents to take responsibility for their children's sex education, the outbreak of war raised new concerns about levels of venereal disease amongst both British soldiers (23000 soldiers hospitalised with sexually transmitted infections) and French civilians (over a million cases of syphilis and gonorrhoea) (Selvin, 1984). Such difficulties with sexually transmitted infection contraction is not unusual in the case of outbreaks of war as soldiers are more likely to utilise sex workers, especially when access to large-

scale prostitution often occurs in war torn areas (Plummer et al, 1991). Following a review by the Royal Commission on Venereal Disease (1916), guided by the British Social Hygiene Council (previously National Council for Combating Venereal Disease), the government pushed for education in relation to sex to be undertaken by those in the position of teaching children, including parents and teachers. Unfortunately, the teaching of such subjects was relatively short lived as the Board of Education and Chief Medical Officer indicated uncertainty as to whether teaching children about sex was “advisable or practicable” (Board of Education, 1930), whilst governmental funding was withdrawn. Consequently, sex education programmes went from being mandatory to advisory, taking the form of suggestions about what could be taught (Hall, 2000).

Until the Second World War, the battle between society’s moral view on sex and the developing ideas surrounding sexual behaviours and attitudes continued, often spurred on by the Board of Education (Hall, 2000). Interestingly, although the Board felt that sex education programme should be part of courses such as biology, the Board did highlight in the report that, although most programmes targeted the thirteen and above age range, it was advantageous to commence sex education once the child began asking questions. At this point that the first signs of relationship training were described in relation to ensuring that adolescents gained greater understanding and control of their sexual impulses and associated emotions, to ensure that areas such as marriage and parenthood were prepared for. This was thought necessary to reduce the destructive force of developing sexuality and sexual impulses in light of the impact of the war and increase in extra-marital pregnancies and venereal diseases. Unfortunately, the impact of the Second World War upon finances delayed any further development in the implementation of sex education within schools (Pilcher, 2004).

A significant shift in attitude was made in the late 1950s with the fourth edition of the handbook of health education in 1956, which contained a chapter devoted to sex education and information discussing specifics surrounding sex and reproduction (Ministry of Education, 1956). This allowed the emphasis of curriculum development to develop and explore what a child should be taught, including a wide range of issues such as puberty developments and social issues that occur in conjunction with

alcohol and subsequent sexual misconduct. This attitude change concerning sex education for children carried on into the 1960s when responsibility for such education became shared. Initially it had been agreed that the best source of teaching was parents, however the importance for schools to provide specific sex education was strongly emphasised in conjunction with parental co-operation. The change in perception was based upon a number of social pressures including increases in the rates of extra-marital births and teenage marriages or pregnancies. Also, the role of young people in society was changing as they became more sexually promiscuous, indicated by the increase in venereal diseases (Schofield, 1968), and the improvement in young people's social and cultural position.

The 1970's brought realisation by central government about the need for an appropriate school sex education programme and the implementation of a health campaign urging people to use contraception. Generally, the sex education being provided continued to be about the mechanics of sex, often resulting in the separation of boys and girls during the teaching for their own specific versions. However, as the 1970s progressed a more comprehensive programme was outlined in the 1977 edition of "Health Education In Schools" including identification of topics such as homosexuality and masturbation. Also, the recognition that sex was not just for procreation but could be enjoyable too. Additionally, the Department of Education and Science emphasised the rights of children to learn about sex as demonstrated by the Department's insistence that parents refrain from withdrawing their children from sex education as the children would still obtain information from their peers which could be inaccurate (Department of Education and Science, 1977).

As the 1980s arrived, the inclusion of sex education continued with secondary schools being required to provide an outline about the sex education they provided. The 1986 Education Act placed control of sex education into the hands of schools and their governors. However, legislation was also being passed by the then Conservative government (Section 28) stopping the 'promotion' of homosexuality by local authorities, thus impacting upon the schools' ability to provide a full comprehensive sex education programme.

The next decades took sex education into the new millennium in a very different format than previously. Although the new 1993 Education Act ensured that biological aspects became a compulsory part of school teaching, it removed the “non-biological” sections of the curriculum, such as sexually transmitted diseases and the issues of underage sex. Additionally, parental power to remove their child from sex education was reinstated. This remained until the then Labour Government developed new Sex and Relationship Guidance following a report on the teenage pregnancy situation, which provided more comprehensive programme allowing discussion of more than just the mechanics.

3.2.2 What has SRE become?

Since the 2000 ‘Sex and Relationship Education Guidance’, sex education has further developed. Now generally known as “sex and relationship education” (SRE), it includes the emotional, social and physical aspects of growing up, relationships, human sexuality and sexual health, not just about the sexual act (Alldred & David, 2007). The focus upon relationships has become an important aspect following government campaigns, such as “This is Abuse”, concerning the levels of relationship abuse occurring within the teenage population. In all maintained secondary schools, it is now a legal requirement that, in addition to the biological aspect, schools must provide additional information relating to relationships (DfE, 2000). Presently, this is not the case in primary schools, but will become mandatory in 2020.

Although the details of SRE programmes are decided by the individual school, there are four main aspects consistently highlighted in the various framework suggestions. These are:

- The development of the young person’s confidence and responsibility in order to develop their overall abilities.
- Preparation for the person to become an active citizen.
- Ensuring a healthy and safer lifestyle
- Developing relationship skills and to also demonstrate respect for people’s differences.

Long (House of Commons), 2014, p4-6

Unfortunately, a number of reviews have demonstrated how much further school programmes have to go. In 2008 a review recommended that SRE became part of the mandatory curriculum and was explicitly highlighted in the Children, Schools and Families Act 2010 as a requirement. These included compulsory SRE as well as all children having a minimum of one year of SRE but there was a lack of key points in the final Act. The issue of compulsory SRE continued during a review by the Department for Education (2014), and in a summary report two years later. It argued that SRE should remain a non-statutory subject in order to enable teachers to provide a flexible and high quality programme based upon the teachers' understanding of their pupils needs. However central government did provide grant funding for the PSHE Association to work with and support schools in implementing the school's programme in an attempt to improve the teaching quality.

In July 2013, following the findings of Ofsted's report that the sex and relationship education being provided by a third of schools was inadequate, Baroness Gould of Potternewton discussed in Parliament the opposition against the government's proposed curriculum changes and how the Department of Health were going to monitor the progress of the curriculum. The concerns raised centred upon a reduction in information provided within the new curriculum as well as the lack of consultation with those who receive the information; namely young people. The government recognised that the information young people required was key to their sexual development, but no method of tracking progress was available. Recently, the Conservative Government performed a review of SRE within schools which has resulted in MPs voting for relationship education to be compulsory in all schools and sex education to be mandatory in all secondary schools. Initially this was to be from September 2019, but this has been delayed until September 2020 due to milestones not being met by the government. Prior to this date, the governmental recommends schools should commence teaching the new subjects from September 2019 so that systems are in place (DofE, 2019). The government recommendations state that all secondary schools, including local authority schools, free schools, faith schools' alternative provisions, independent schools and special schools will teach Relationships and Sex Education, whilst all primary schools will teach Relationships Education. Additionally, the programs provided in primary schools will be tailored to the needs of the pupils, and health education will be a compulsory subject in all state funded schools. Parents and carers will be

able to withdraw their child from all elements of the sex education aspect within primary school or in secondary schools until three terms before the child reaches secondary school. Parents and Carers are not allowed to withdraw their child from the relationship aspect at any point during their child's school life. Unfortunately, the change in the teaching of sex and relationships within school has caused controversy following a few primary schools implementing the relationship aspect. This has resulted in several parents removing their child from some schools in Birmingham and even protesting outside of school (Ferguson, 2019) primarily due to the teaching of same sex relationships, but not the actual sexual act.

3.2.3 Sex education and Intellectual and developmental disabilities

Whereas sex education for “neuro-typical” individuals had a slow but steady development, the education for individuals with intellectual and developmental disabilities has only occurred in relatively recent times. Studies have demonstrated a lack of much positive change in the situation, both in the UK (Simpson et al, 2006) and other countries (Griffiths et al, 2008). As with their neuro-typical counterparts, individuals with intellectual and developmental disabilities are helped in keeping safe from sexual abuse via the use of sex education (Murphy, 2003). This is imperative when such individuals are at a disadvantage in their level of knowledge as well as limited experiences and opportunities relating to sexuality (McCabe, 1999; Murphy & O’Callaghan, 2004). This was further discussed in an investigation of risky sexual behaviours amongst youngsters in a number of East London based schools (Sinha, et al, 2005). This highlighted the lack of support and education available, whilst a high proportion of teenagers with intellectual and developmental disabilities were engaging in sexual relationships. Further statistical results obtained in Wolverhampton from one school for individuals with intellectual and developmental disabilities suggested that 40% of their female ex-pupils would become teenage mothers within 18 months of leaving the school (Heer, 2008).

The foundation for change in relation to sex education and individuals with intellectual and developmental disabilities has been provided by a number of key players (e.g. Brown, 1994; Craft, 1994; McCarthy & Thompson, 2010), but even in the 1990’s the need for such education for

individuals with intellectual and developmental disabilities was still being questioned (Katoda, 1993; Newens & McEwan, 1995). Central to this has been perceptions that such individuals are either “asexual, or oversexed, innocents or perverts” (Brown, 1994; Blunn et al, 1984)) (as discussed in Chapter Two). This has led to the minimalization of sex and sexuality upon individuals with intellectual and developmental disabilities thus reducing the need for sex education which some believe encourages inappropriate sexual behaviours. However, such consequences were not borne out in Dukes and McGuire’s small study (2009) which explored whether the capacity to make sexually related decisions would change following the use of educational interventions to increase knowledge of this area. This involved four participants with a moderate level of intellectual and developmental disabilities being assessed in four knowledge areas: sexual safety practices, physical self, sexual functioning, and choices and consequences in sexual matters. Measures were taken pre and post intervention using the SCEA (Kennedy, 1993) tool and the sex education intervention came from *Living Your Life-The Sex Education and Personal Development Resource for Special Education Needs-Revised Edition* (Bustard, 2003). The results indicated that there were improvements in all the areas for all four participants, and, as a consequence, indicated that the participants’ capacity to make sexuality-related decisions had improved. Although the study disproved previous perceptions about sex education and sexuality with individuals with intellectual and developmental disabilities, such perception has generally persisted. For example, it has been reported that often there is a ‘boys will be boys’ attitude concerning such issues which occurs (Bunston, 2000). Fortunately, since the 1980’s there has been a growing move toward providing comprehensive sex education to those with intellectual and developmental disabilities. This will be explored in more detail within the systematic literature review.

‘Knowledge is power’ is as relevant for individuals with intellectual disabilities regarding sex and sexuality as in any other situations. Possessing appropriate levels of information and knowledge has been highlighted by many as imperative to an individual with intellectual and developmental disabilities (Lunsky et al, 2007; Isler et al, 2009; Kijak, 2013). In some studies, it has been hypothesised that an increase in knowledge and the ability to make appropriate decisions is an important aspect for an individual to develop in order for them to more effectively recognise and protect themselves from abuse (Khemka & Hickson, 2000). This knowledge has not been exclusively about sex and

sexuality, but also about specific topics (e.g. HIV and sexually transmitted diseases). As with the general topics, studies have shown how individuals with intellectual and developmental disabilities frequently possess less knowledge than their neurotypical counterparts (McGillivray, 1999). Often this has been related to the use of generic health promotion campaigns which do not differentiate the information to the cognitive abilities and lifestyles of individuals with intellectual and developmental disabilities (McCarthy & Thompson, 1994). Unlike some of the preconceptions that have occurred, such studies have highlighted how a lack of education impacts upon the ability to make appropriate choices and so empower individuals with intellectual disabilities in relation to their sexuality and needs (Swango-Wilson, 2008; McDermott et al, 1999), including the recognition of sexual abuse (Murphy, 2003).

The recognition for appropriate comprehensive sex education has developed from the awareness of the vulnerability of individuals with intellectual and developmental disabilities, especially as the move toward more community-based care progressed. The move to such community-based care exposed some individuals involved to higher levels of exploitation and abuse, as well as sexually transmitted diseases and HIV related illnesses that 20th century society now faced, although this was not the case for all involved as some individuals were much safer in the community. In addition, a range of authors had previously elaborated on such issues and identified a range of relevant factors:

- Impaired impulse control and consequential thinking (McGillivray, 1999)
- Reluctance by service providers to provide relevant sex education (McCabe, 1993)
- Vulnerability to sexual abuse (Turk & Brown, 1993; Sobsey, 1994)

Unfortunately, the level of SRE provided for individuals with intellectual and developmental disabilities by schools often only deals with the biological aspects (Family Planning, 2010), which has been criticised by many, particularly those in receipt of the teaching; children and young people (Mackenzie & Watts, 2013). The inclusion of individuals with intellectual and developmental disabilities in the planning and development of sex education curriculums has been suggested by researchers (McCabe, 1993; Swango-Wilson, 2011) to increase the effectiveness and appropriateness

of the programmes. Often programmes for individuals with intellectual and developmental disabilities have been based upon a reactive approach (Boehning, 2006; Gerhardt, 2006) which increases the likelihood of misinformation occurring (Gougeon, 2009). Comprehensive sex education programme content for individuals with intellectual and developmental disabilities has been discussed and developed since Craft et al (1983) described a programme for individuals in hospital settings and those with milder intellectual disabilities living in the community. Such programmes reflected the generic programmes taught in mainstream school, emphasising the physical aspects although utilising visual materials to assist individuals with intellectual disabilities. Further programmes (e.g. Kempton, 1988) provided a more structured approach using visual support which has continued to develop.

Often development in sex education programmes centres upon the materials, as new technology improved (e.g. greater use of videos (Frawley et al, 2003)). The other area of development relates to providing sex education to individuals with severe learning disabilities (Dixon, 1993; Downs & Craft, 1999). The Downs & Craft study (1999) trained the care staff in relation to the appropriate support mechanism required to help individuals with SLD and their sexual development. Unfortunately, although progress has been made in the core content within sex education programmes, programme developers have missed the inclusion of the main component, individuals with intellectual and developmental disabilities. Often the individuals' wants and hopes are different to views of family and staff (McCarthy & Thompson, 2010). Further exploration of the sexual needs of individuals with intellectual disabilities highlights a shortfall in the current practices in the teaching of sex education, namely the "ignored curriculum" (Gougeon, 2009, p277). This concept centres upon the idea that there are aspects of sex and sexuality that are learnt by typically developing teenagers through everyday life and peer interactions. Such a curriculum is often unavailable to individuals with intellectual disabilities as much of that learning occurs during social times when such individuals are generally under adult surveillance often limiting their experiences and is in contrast to their neuro-typical counterparts (Watson et al, 1999). To ensure the inclusion of such aspects, it has been suggested that a critical pedagogical approach be utilised (Gougeon, 2009) in order to provide a more inclusive education (Shakespeare et al, 1996), that involves the students thus ensuring its relevancy

to their daily lives. Such knowledge and experience in turn should aid individuals with intellectual disabilities to more effectively participate in the wider social world (McLaren, 2007).

3.2.4 Sex Education and Autistic Spectrum Condition

Although positive change in policy has occurred, one area where progress continues to be an issue relates to pupils with autistic spectrum condition. For years there was a belief that people with autistic spectrum condition possessed no drive for intercourse (DeMyer, 1979) or that only a few had sexual problems (Dewey & Everard, 1974). However, this has been shown to be incorrect, with a range of research material (Haracopos & Pedersen, 1992; Hellemans et al., 2007) highlighting the opposite. These studies have recognised a lack of social skills does not result in a lack of interest in more intimate relations with others. However, there are examples across schools (Speirs, 2006) that failings in the current curriculum are still occurring for students with autistic spectrum condition (Hatton & Tector, 2010). These failings occur despite Government recognition that the need for pupils with disabilities, including those with autistic spectrum condition should be examined:

“SRE should be inclusive and meet the needs of all young people, recognising that existing SRE provision does not always take sufficient account of issues such as sexuality, disability, ethnicity and faith.”

(Department for Children, Schools and Families, 2008, p. 2)

Hatton and Tector (2010) examined the curriculum on a micro-level within a school specifically for people with autistic spectrum condition and attempted to develop a more appropriate curriculum. Although limited, Hatton and Tector highlighted a need for curriculum adaptation for those pupils with autistic spectrum condition. Additionally, anecdotal feedback to the present author from sexual health staff has illustrated how teaching students with autistic spectrum condition in large mainstream classes reduces the ability to provide time for detailed exploration and clarification for those who need it, specifically those with autistic spectrum condition. This raises concerns about whether the student with autistic spectrum condition fully develops the knowledge and skills needed to understand their sexuality and thus keep them safe. Such considerations are important when

research indicates the sexual interest experienced by people with autistic spectrum condition is comparable to that of the general populace (Henault & Attwood, 2002).

3.2.5 Programme Evaluation

Reviewing and evaluating sex education programmes has been recognised as an important part of programme development (Craft, 1994; Newens & McEwan, 1995). Achieving this involves assessing the ability of the professionals implementing the programme, as well as examining the student needs, resources and programme content (Newens & McEwans, 1995; Cambridge, 1998; Haight & Faching, 2001; Lafferty et al, 2012), as well as parental feedback (Craft, 1994).

A review of sex education programmes (Grieveo, McLaren & Lindsay, 2006) since the 1980's highlighted how sex education programmes frequently do not provide statistical evidence indicating effectiveness and reliability of the programmes. Frequently early programme developers made large claims about the success of the programmes but without the evidence, such as Kempton's 'Life Horizons' slides (1988) and 'Picture Yourself' training pack (Dixon & Craft, 1992). With time, programme developers have utilised evaluation methods such as observation in relation to the implementation of sex education was used (Newens & McEwan, 1995) to assess the effectiveness of both the programme and the professionals leading it. In many cases, sex education programmes have been compiled by professionals who have a particular interest in the subject. Often this is done on a needs basis and little is ever known about the effectiveness of such programmes (Schaafsma et al, 2013). A review of the evaluation of such programmes shows how similar methodology is used, namely the assessment of acquired knowledge by participants (Hayashi et al, 2011; Lawrence & Swain, 1993) and occasional attitudinal changes, including changes in behaviours (Lindsay et al, 1992).

3.3 Systematic Literature Review

So far, the emphasis within this chapter has been upon some of the key factual elements relating to the development of sex education programmes and the need to develop sexual knowledge, both for

the mainstream population and individuals with intellectual disabilities, autistic spectrum condition. However, the discussion surrounding the specific factors that impact upon how individuals with intellectual disabilities, autistic spectrum condition develop adequate sexual knowledge has been limited, specifically in relation to the sex education programmes within schools that are used with this group of individuals. In an attempt to effectively explore this element, a systematic literature review was conducted of relevant articles and studies with the aim of identifying and reviewing themes that may impact upon sex education programmes for this specific group.

3.3.1 Search Methodology

The search for relevant articles was undertaken using the following keywords as search terms:

Autism keywords

- Autis*
- Asperger
- AUTISTIC SPECTRUM DISORDER
- AUTISTIC SPECTRUM CONDITION

Intellectual Disabilities keywords

- Learning disabil*
- Intellectual disabil*
- Developmental disabil*
- Mental retard*

Each set of keywords was searched alongside the term “sex education”. No date restriction was placed on the search which was performed via three main databases; Google Scholar, PsycInfo and Medline. Furthermore, relevant articles were identified via the reference lists from each initial article, as well as a search of a specific journal, “Sexuality and Disability” which was identified as being an effective source of material. The initial search was performed in November 2013, repeated in April 2014 and again in May 2019.

3.3.2 Inclusion and Exclusion Criteria

The title and abstract of each relevant article identified via the search was reviewed to ensure that they met the inclusion criteria:

- English language
- Peer reviewed
- Examined issues pertaining to sex education; whether this was an active issue or performed retrospectively.
- Participants with a diagnosis of an autism spectrum condition according to either ICD-10 or DSM-IV-TR criteria as measured using an appropriate assessment tool or,
- Participants with a diagnosis of intellectual disability as measured using an appropriate tool.
- Reported data from participants, including attitudes to sex education, evaluations of sex education or sexual knowledge

Articles were excluded if:

- They only reported about sexuality issues without any connection to the issue of sex education.
- They were dissertations
- They were reviews or book chapters

Initially the results provided 1725 entries across the databases chosen, however reading through the abstracts showed that a huge proportion of these were centred upon the diagnostic procedure in relation to autistic spectrum condition and Asperger's Syndrome as well as issues that were not related to the topic of sex education. As a consequence of this and the removal of duplicates, a total of 42 papers were identified as meeting the specific search criteria, although the majority of these centred upon Intellectual and Developmental Disabilities or Learning Disabilities rather than more specifically autistic spectrum condition or Asperger's Syndrome. Each of the remaining articles that appeared to meet the inclusion criteria as assessed via the abstract, was reviewed in full to assess the quality of the study as well as confirm its relevancy to the review. As a consequence, 13 studies were subsequently excluded because although they talked about aspects of sexuality, for example, sexual behaviour (Van Bourgondien et al, 1997), touching people in relationships (Sullivan et al,

2013), meanings of close friendship (Knox & Hickson, 2001), the studies did not discuss sex education issues. None of these excluded studies appear in the Tables of resulting papers, but they are considered in the discussion where relevant. As a result, 29 studies were included within the review from the initial two searches. A further three were identified in the final review (the search in May 2019). Figure 3.1 shows a Flow Chart outlining the numbers of articles found at every stage of the review resulting in the final number.

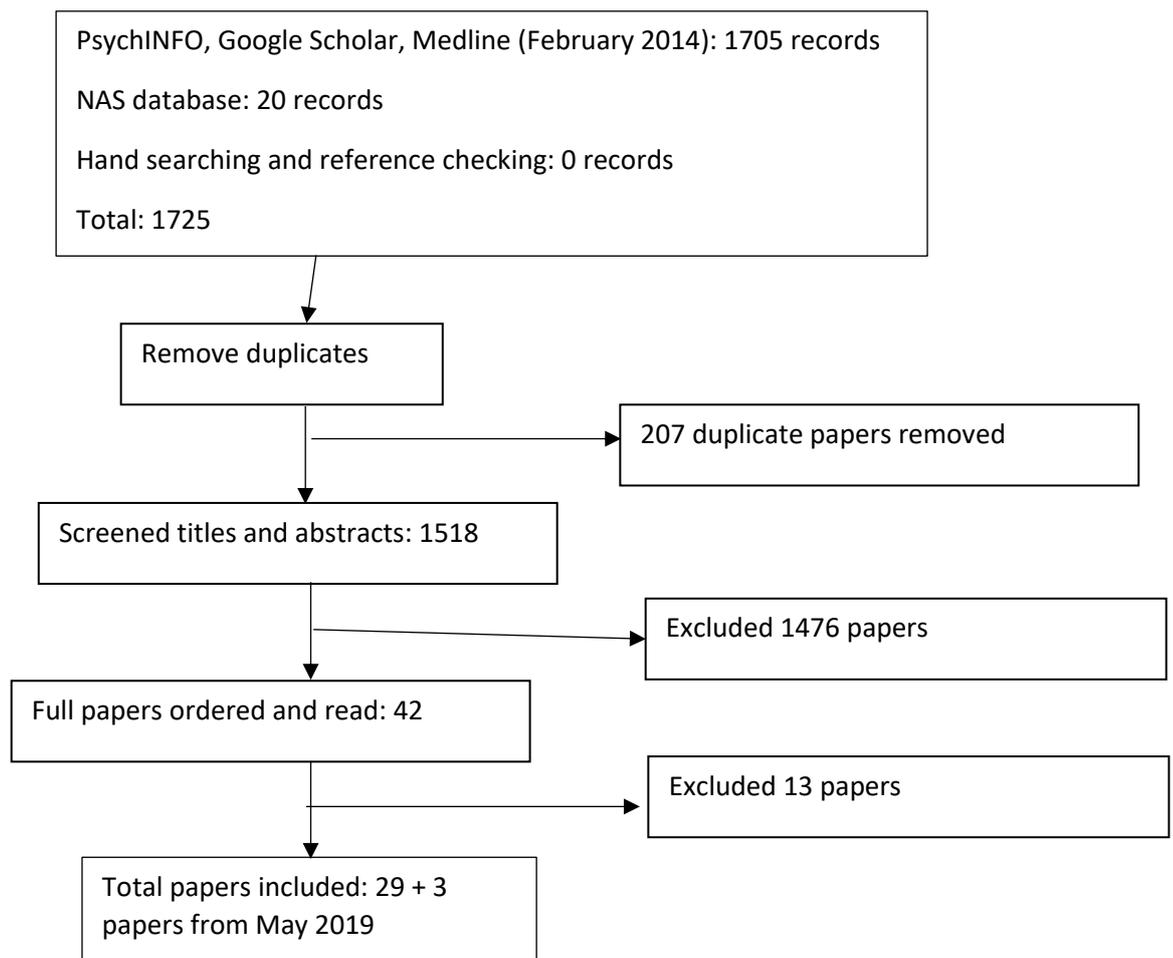


Fig.3.1 – Flowchart outlining article results for literature review

3.3.3 Analytical Process

The research papers identified as being relevant for the present study were analysed with a focus on a number of issues within sex education. Initially these were:

- Sex education programmes for individuals with Intellectual Disabilities and/or Autistic Spectrum Condition or Asperger’s Syndrome
- Implementation factors impacting upon the sex education programmes
- Evaluation of sex education programmes

In addition, any further issues that were highlighted within the review as being prominent amongst a number of the papers were also included in the final review. Within the various research papers, a range of differing methodologies were used with various focuses and so the data obtained from the review were descriptive in nature. The final data were tabulated outlining the main aspects of each study (See Table 3.2).

Table 3.2 – Literature Review Results

Author, Country	Study Population	Number of participants	Methods	Outcomes	Themes Identified
Brown & Pirtle (2008) USA	Individuals providing direct care or instruction to individuals with ID	40 participants contacted by letter	Using Q-sort form board participants were asked on one to one basis what their beliefs concerning the sexuality of individuals with ID. Follow up interviews with participants	Agreement that sex education should include discussion about morality and provided to anyone who can understand.	Sex Education Programme (Intellectual & Developmental Disabilities) Impact of attitudes upon the implementation of sex education programmes
Dekker et al (2015) Netherlands	Individuals ages 11-19 years with ASD who attended an inpatient or outpatient clinic in the South West of the Netherlands. The majority of participants were male (77%).	30 11-19 year olds and all remained on the program until the end	Pre and post psychosexual knowledge testing based upon an existing Dutch high school biology test regarding sexual knowledge for adolescents. A programme was developed	The result indicated that there was an overall improvement in the psychosexual knowledge of all participants. There was also an indication that the age and ability of participants had an impact upon this difference.	Specific impact of ASD/Asperger's Syndrome on sex education programmes

			for the pilot scheme called the Tackling Teenage Training Program. This involved 18 group sessions exploring a range of topics, such as friendships, puberty, sexuality and internet use.	This was felt to be because those with less knowledge or understanding at the start of the program gained more from the information compared to others. Also, the study highlighted the need for further evidence based programmes to be developed.	
Graff et al (2018) USA	Individuals with intellectual disabilities attending an inclusive postsecondary program	55 students with intellectual disabilities aged 18-27. The participants came from students within the first 4 years of the program and the mean ages were all over 20 years	The Positive Choices program that had been developed by the Oak Hill Center for Relationship and Sexuality Education (CRSE) was utilised. The study utilised pre and post-tests developed for the study which was related to the five chapters in the Positive Choice program.	Not all the chapters were taught due to time constraints (The life cycle chapter was left out). Results indicated an increase in overall knowledge. There were areas where participants seemed more motivated to understand due to specific needs, e.g. learning about relationships as they were wanting to have one with other participants. There were issues relating to the varying ability levels of participants which needs further exploration	Sex Education Programme (Intellectual & Developmental Disabilities) Impact of attitudes upon the implementation of sex education programmes

Haight & Faching (2001) USA	6 Students certified learning disabled from a small rural school district, attending 4 mainstream classes and one period in a resource room	6 students (3 males, 3 female) aged between 15 yrs to 17yrs. All certified as having a learning disability. IQ (WISC-R) average (n=2) below average (n=4)	Pre and post 6 session sex education programme (<i>Sexuality, Love and Maturity</i>)	Increase in mean score post-test (68% pre, 95% post). Results indicate that students with ID can learn concepts in human sexuality, but further work required	Sex Education Programme (Intellectual & Developmental Disabilities)
Hatton and Tector, (2010) UK	15 individuals with ASD who above school age were (further details were unavailable) initially identified, 12 respondents.	4 able individuals with ASD from the 12 were involved with interviews.	Initial questionnaire (15 sent out and 12 returned) examining experience of sex education followed by three discussion groups. Semi structured interviews with 4 able individuals with ASD	4 of interviewees had had sex education. All four wanted to have understood themselves more as well as about areas such as friendships.	Impact of attitudes upon the implementation of sex education programmes Specific impact of ASD/Asperger's Syndrome on sex education programmes
Hayashi et al (2011) Japan	Adults with ID (19-45 years) from a <i>tsukinryo</i> a welfare facility in Osaka, Japan	Experimental Group: 17 participants, average age of 29.5 years. N= 15 with ID and n=2 with asd and id. N=9 mild ID, n=7 moderate ID, n=1 severe ID according to DSM-IV. 13 males and 4 females Control Group: 17 participants, average age of 30.9 years. N=13 with ID and n=4 with asd and ID. N=7 mild ID, n=8 moderate ID, n=2 severe ID 11 males and 6 females	Kikuchi's Scale of Social Skills (KISS-18) self-assessment questionnaire to assess social skills. Additional questions at end of each of the 8 sessions to explore specific programme issues	The success of incorporating social skills within sex education programme was higher in control group but may have been influenced by most in group wanting to live independently so providing additional motivation.	Sex Education Programme (Intellectual & Developmental Disabilities)
Isler et al (2009) Turkey	Pupils over 15 years old from an occupational school. All pupils had mild or moderate ID and	60 students with mild or moderate ID aged from 15-20 years. (22 girls (36.7%) 38 boys (63.3%)) 27 (45%) between 15 and 17, 33	Questionnaire developed for the study including demographic details and	Over half stated did not receive sexuality education. Generally gained knowledge from other areas, primarily family (43.3%). Boys	Sex Education Programme (Intellectual & Developmental Disabilities) Impact of attitudes upon the

	chose to participate in the study.	(55%) between 18-20 years	sexual knowledge.	had more difficulty recognising gender-specific differences. Over half of boys admitted to masturbation but only 18.4% of boys knew masturbation in public toilets was illegal.	implementation of sex education programmes
Katoda (1993) Stockholm & Tokyo	Parents and teachers of children with ID (mainly mild to moderate) in Stockholm and Tokyo. Each of the children had also be part of the study but results written up separately.	Stockholm 41 parents (36 females and 5 males) of young people with ID, 20 teachers (17 females 3 males) within the relevant schools. Tokyo 106 parents (94 females and 12 males), 111 teachers (48 females and 63 males)	Questionnaire developed for research. Parents one consisted of background information of family, child's interest in relation to sex and items relating to relationships. Teachers one consisted of similar questions but added some concerning sex education programmes	Majority of parents were mothers of young children (73% Stockholm and 87% in Tokyo). Most children reported to have entered puberty. More parents in Stockholm had talked about sex with children (95%) than in Tokyo (65%). Such differences were similar throughout the questionnaire which was felt to be a cultural reflection. Although in both countries, teachers taught about health and sex education, less did it in a class setting in Tokyo than Stockholm (15% compared 65%). Generally, Stockholm scored higher on all aspects compared to Tokyo	Impact of attitudes upon the implementation of sex education programmes
Kijak (2013) Poland	People with mild ID from 11 schools and special institutions in Poland. All had to be aged 18-25 and have IQ level that was average for someone with higher degree of ID	People with mild ID (42 female, 91 male) age ranges 17-21 (n=96) 22-25 (n=37). Primarily middle to late pubescent stage	Interview schedule developed for the study utilising appropriate visual prompts. Looked at Knowledge surrounding sex and sexuality (body parts, insemination, pregnancy. Also, Nurse	Knowledge about fertilisation was good in over half of participants, but a high proportion lacked knowledge about childbirth (81%). Results showed that although people with HDID have sexual experiences but not enough knowledge	Sex Education Programme (Intellectual & Developmental Disabilities) Impact of attitudes upon the implementation of sex education programmes

			(Doctor) Survey on the Sexual Development Assessment of ID people to supplement the survey		
Lafferty et al (2012) Northern Ireland	Family carers recruited across NI through voluntary organisations and then interviewed by researchers, Professionals recruited from various disciplines following interview and Frontline Staff recruited from social care day centres and supported accommodation services across NI.	22 carers, mostly mothers; 24 professionals (15 female and 9 males) mostly LD nurses (n=8) and social workers (n=5); 24 frontline staff (23 female and 1 male)	Group interviews (4-19) including vignettes for staff and trigger questions for parents. Semi-structured 1:1 interviews with professionals and family carers.	Is RSE needed? Family carers and frontline staff want the individual to have RSE but did not receive it. Professionals feel emotions need to be understood	Sex Education Programme (Intellectual & Developmental Disabilities) Impact of attitudes upon the implementation of sex education programmes
Lawrence & Swain (1993) UK	Student group participating in the 1988 Year Group of the North Tyneside College 'Life Preparation' course. All had previously attended educational establishments for students with SLD	12 males and 5 females. All but 2 students lived in family home. All students were 19yrs except 1 male who was 22yrs.	Review of sampled teaching session transcripts. Semi-structured interview with each participant	Mechanics of sexual intercourse are positively taken on board by students. Difficulties in relation to the broader abstract issues such as relationships and feelings. Suggestions that more visual approaches needed. Generally, there are difficulties relating to evaluating such programmes.	Sex Education Programme (Intellectual & Developmental Disabilities)
Lindsay et al (1992) Scotland	All subjects had mild or moderate ID and had been referred for sex education programme	Two groups: Group 1 contained 46 subjects seen in groups of 6 to 8. (32 lived at home attending day placements, 14 lived in hospital. (average age 28.7 years, average IQ 58.3, 26 males and 20 females Group 2 (control group) contained 14 subjects. 8 at home, 6 in hospital, average age 26.2 years, average IQ 58.1, 7 males, 7 females.	Group 1 tested before and after programme then 23 tested at 3 months follow up. Group 2 tested and re-tested after 4 month interval. Assessments based upon previously published assessments and comprised	Post training scores for Group 1 demonstrated considerable improvement in all sections covered with some drop on follow up in relation to intercourse and childbirth. Baseline knowledge on all areas were not significantly	Sex Education Programme (Intellectual & Developmental Disabilities)

			of seven sections including parts of the body, puberty, birth control and STIs.	different between groups and no significant change in the knowledge level overall of Group 2.	
Löfgren-Mårtenson (2012) Sweden	Participants were randomly chosen from special education high schools in Malmoe, Sweden. All had ID	16 students, seven boys and nine girls, aged 16-21 years. All attended national and individual programs in senior high schools with varying degrees of ID.	Face to face interviews. 5 cases in collaboration with a graduate student of gender studies.	Responses to questions indicate lack of knowledge surrounding sex education including what is it about. Lack of understanding about what was taught and the need for more information at an appropriate level. Need for more appropriate teaching methods in relation to material used and visual aids. Difficulties with retention of knowledge, especially social aspects. Identifying the need to have someone to talk to following sex education programme. The need to explore social and sexual scripts within sex education.	Sex Education Programme (Intellectual & Developmental Disabilities)
Lunsky et al (2007) Canada and USA	From dataset of 276 individuals from community and institutional settings who completed the SSKAAT-R field testing looking at	Two groups: 43 males with ID with known sexual offence history (27 =Type I; 16=Type II) ; 48 males with similar levels of ID with no known sexual offence history. Offender group had received significantly higher levels of sex		Those that had had sex education showed no significant differences in sexual knowledge	Sex Education Programme (Intellectual & Developmental Disabilities) Impact of attitudes upon the implementation

	seven knowledge subscales	education than non-offender group (96.1% compared to 51.8%)			of sex education programmes
McCabe (1999) Australia	Three groups – one with mild ID, one with physical disability, one general population. Those with disabilities recruited via sheltered workshop. General population recruited via newspaper advertisement.	ID group (n= 60) (28 males, 32 females, mean age=27.62 years. Physical disability group (n=60) (33 males, 27 females, mean age=28.65). General group (n=100) (40 males, 60 females, mean age=20.1). Certain number of participants had had some form of sex education (52% ID; 56% physical; 90% general)	Sexual Knowledge scales used for each group (SexKen-ID for ID group, SexKen-PD for physical group; SexKen-GP for general group) to assess general sexual knowledge	Significant differences in a number of areas, especially social based areas, with people with ID having lower levels of knowledge than those with physical who in turn had lower levels of knowledge than general population. Source of sex education more limited for ID	Sex Education Programme (Intellectual & Developmental Disabilities) Impact of attitudes upon the implementation of sex education programmes
McGillivray (1999) Australia	Adults with mild/moderate ID who attended sheltered work facilities in a metropolitan region of Melbourne. Comparison group of undergraduate university students completing Business/Humanities degrees	ID group 35men, 25 women. Verbally able aged from 18 to 59 years. None married 33% lived independently (12% on own, 21% with friends) 50% with parents and 17% in staffed community based residential units. Comparison Group 35 men 25 women. None married. Age ranged 18 to 31. 32% lived independently (13% own, 19% with friends) 68% lived with parents	Eight-part assessment instrument developed, including Sexual Experience Inventory, Knowledge of AIDS Test, AIDS Attitude Scale, Condom Knowledge Test, Condom Outcome Scale, Safe-sex Efficacy Scale, Vignettes, Sexual Self-Esteem.	60% of ID sample sexually active compared to 77% of comparison. Knowledge in relation to AIDS highlighted difference between groups (feeling sick having AIDS (88% ID believed this compared to 18% comparison group). Birth control as an AIDS precaution (77% ID compared to 2%). Lack of understanding about how to use condoms was low in ID (87% compared to 25%). Overall	Sex Education Programme (Intellectual & Developmental Disabilities) Impact of attitudes upon the implementation of sex education programmes

				adults with ID have deficits in their sexual knowledge relating to HIV/AIDS compared to normal developing people.	
Murphy & O'Callaghan (2004) UK	Adults with ID from three services for people with ID in South London and Kent. Two comprehensive schools in Kent provided a group of over 16s as a control group.	Adults with ID (n=60; 30 males and 30 females) Mean age 37.6. Mild to moderate ID able to communicate verbally. Tested using WASI. Control Group (n=60; 30 males and 30 females) mean age 16.6 control group as were deemed able to give legal consent.	Sex-K-ID and two measures of abuse developed for the study (The Understanding Consent and Abuse measure, and Five Vignettes developed for study. Both groups assessed with Social Network Map, Test of Interpersonal Competence and Personal Vulnerability and measure relating to understanding of the law on sexual offences developed for this study.	Adults with ID understood significantly less than control group around concerning sexual knowledge. No significant gender differences in ID group but significant in non-disabled group (females scored higher). Vignettes resulted in lower scores from ID group in recall of facts and understanding. Previous sex education made a positive difference on ID scores.	Sex Education Programme (Intellectual & Developmental Disabilities) Impact of attitudes upon the implementation of sex education programmes
Newens & McEwans (1995) UK	Students attending one of two special schools up to the age of 18 with severe learning disabilities.	Two groups- Group A 6 male students age range 16-18. Group B 9 students (7 male 2 female) aged 16-18.	Observations and comparison of the two groups in relation five sex education sessions in each school; Group A led by male specialist community nurse based in community health resource, Group B within normal classroom.	The teacher led sessions benefitted from the ongoing relationship between teacher and pupil allowing greater discussion. Issues relating to the mixed ability	Sex Education Programme (Intellectual & Developmental Disabilities) Impact of attitudes upon the implementation of sex education programmes

			Field notes were then reviewed	of students requiring further 1:1 work. Use of visual material helpful	
O'Callaghan & Murphy (2007) UK	Adults with ID from three services for people with ID in South London and Kent. Two comprehensive schools in Kent provided a group of over 16s as a control group.	Adults with ID (n=60; 30 males and 30 females) Mean age 37.6. Mild to moderate ID able to communicate verbally. Tested using WASI. Control Group (n=60; 30 males and 30 females) mean age 16.6 control group as were deemed able to give legal consent.	Questionnaire developed by researchers to assess participant understanding of sex and the law. 30 questions in total. Both groups assessed with Social Network Map, Sex-K-ID and questions and vignettes from 'Sex and the 3Rs'	Adults with ID understood less than control group around sex and the law (e.g. 55/60 control knew legal age of consent, 15/60 ID group).	Impact of attitudes upon the implementation of sex education programmes
Parchomiuk (2012) Poland	Professionals working with individuals with ID in Lublin province of Poland in various care and educational settings.	98 professionals (81 women and 17 men) aged between 20-55. Group included special educators (40), social workers (34) nurses/physiotherapists (15), others (9)	Semantic differentials looking at respondents emotional-evaluative attitude. Questionnaire designed to determine nature of experience the respondents had with sexuality of people with ID	Interpretation of what is sexualised behaviour varied with many educators highlighting hand holding.	Sex Education Programme (Intellectual & Developmental Disabilities) Impact of attitudes upon the implementation of sex education programmes
Pownall et al (2012) UK	Mothers of young people with mild ID and mothers of young people without ID or other disabilities. Age range of young people were 16 and 24 years. Mothers identified through national voluntary, non-profit organisation. Each child had to be verbally able to recount everyday events and to	Equal group sizes (n=30). Id Group included 4 with additional physical disabilities and 3 had siblings with ID. All lived at home with mothers except 1 in residential care.	Demographic questionnaire examining a range of issues including gender, religion and family composition. UK National Statistics-Socio-Economic Classification for social position. Adaptive Behaviour Scale Mothers' attitudes and beliefs	Source of sexual information reported similar between groups re: family (n=12-15), School/college (n=11-14), but difference in leisure (social) (n=4/5 ID; n=11/14 non ID). Topics discussed by mothers of ID were fewer than non ID and discussed at a	Sex Education Programme (Intellectual & Developmental Disabilities)

	describe their feelings		concerning sexuality questionnaire. Developed for the research	later age. Mothers of ID children felt that child was more cautious about discussing sexual topics than non ID. Support for ID families were fewer.	
Rohleder (2010) South Africa	Four individuals based in non-governmental organisation providing support to schools and organisations. Chosen with help of manager.	2 groups of three teachers from two different schools for focus groups.	Individual interviews for four individuals using semi-structured interview schedule followed by focus group. 2 focus groups containing three teachers from each school.	Identified perceived resistance by other parties against sex education for individuals with ID. Anxiety experienced by parents and staff about talking about sex, encouraging "immoral sexual relationship". Religious views (Christian) impacted upon implementation of programmes. Implementation issues in facilitating appropriate programmes.	Impact of attitudes upon the implementation of sex education programmes
Rohleder & Swartz (2009) South Africa	Key individuals associated with an organisation that serviced a number of smaller organisations and schools for people with ID.	Four individuals; director, 2 facilitators of sex education programme, 1 facilitated education programme at an organisation for persons with ID. 3 teachers working at two different schools for individuals with ID	Individual interviews and group interviews with 3 teachers	All participants were in agreement about sex education, but conflicts between sex education (including homosexuality and contraception) and encouraging sexual activity against their	Impact of attitudes upon the implementation of sex education programmes

				Christian morals. Conflicts about teaching privacy but not being able to provide it. Fears of encouraging promiscuity through teaching sex education.	
Ruble & Dalrymple (1993) USA	Parents of children 9 yrs and older with ASD. All individuals were on a database at the Indiana Resource Center for Autism	350 were identified, 116 responded but 16 were discarded due to incomplete data or incorrect age. 85% mothers, 8% both, 5% fathers and 2% others (grandparents) participated.	The Sexuality Awareness Survey (SAS) developed and completed by each participant	Sex education for less able children was less relevant to their child. Parental concern about vulnerability and misinterpretation by others. Parents want more information about sexuality	Sex Education Programme (Intellectual & Developmental Disabilities) Impact of attitudes upon the implementation of sex education programmes Specific impact of ASD/Asperger's Syndrome on sex education programmes
Ryan & McConkey (2000) Ireland	Staff involved in ID services and those teachers and care staff working with teenage pupils in special schools within geographical area covered by one community health trust in N Ireland. 17 'centres' identified	150 participants working in the schools and care centres (Community HSS staff (37%); Private Sector Employees (23%), Voluntary Sector employees (22%), Education personnel (18%). 45% held professional qualification. Various times working with ID (40% - 10 yrs or more; 23% - 5 to 9 yrs, 30% - 1 to 4 yrs)	Self-completion questionnaire developed based on previous research and pilot work. Listed 10 statements about Sexuality using five point Likert scale.	Majority of respondents agreed to sex education for people with ID and discouraged from 'one-night stands'. Also, agreement about marriage, masturbation and privacy.	Sex Education Programme (Intellectual & Developmental Disabilities) Impact of attitudes upon the implementation of sex education programmes
Schaafsma et al (2013) Netherlands	Sex education programmes targeted at people with ID in the Netherlands. Excluded programmes within schools and those focused on preventing sexual abuse	5 sex education programmes with 11 programme developers	Interviews based upon adaptation of the Intervention Mapping process	Implementation affected by individual levels such as IQ and knowledge, organisational policies, individual's view on sex and experience on internet. Outcomes identified included knowledge, empowerment and tailoring the programmes.	Sex Education Programme (Intellectual & Developmental Disabilities) Impact of attitudes upon the implementation of sex education programmes

				Range of approaches used in development, primarily tailoring, images and guided practice methods	
Schaafsma et al (2014) The Netherlands	Paid Carers working in an organisation specialised in the care of people with mild and moderate intellectual disabilities. Some of the carers also taught sex education	1475 paid care staff were contacted with 630 completing the survey (43%). The final number involved dropped to 163 paid staff who were directly responsible for the wellbeing of clients. 85% of participants were female with a mean age of 37.63	An online survey developed for the study using a Likert Scale to explore areas including attitudes, and involvement with sex education	Only 39% of participants were identified as teaching sex education to clients. Some attitudes highlighted that staff felt the clients did not need sex education as "they were not sexually active" or "did not want to know about sex education". Often sex education was implemented in a reactive manner as a response to issues that had arisen	
Stokes & Kaur (2005) Australia	Parents of typical children (n=51) and children diagnosed with Asperger's Syndrome or High-Functioning Autism (n=23). All children were aged 10-15, and parents were chosen randomly.	Parents of typical children (n=51) and children diagnosed with Asperger's Syndrome or High-Functioning Autism (n=23). All children were aged 10-15, and parents were chosen randomly.	The Sexual Behaviour Scale was completed by parents in relation to child's social behaviour, privacy awareness, sex education, sexual behaviour and parental concerns.	Differences in relation to all areas with typical children possessing greater knowledge. No significant difference in relation to the likelihood of an individual displaying inappropriate sexualised behaviour and also level of sex education.	Sex Education Programme (Intellectual & Developmental Disabilities) Specific impact of ASD/Asperger's Syndrome on sex education programmes
Swango-Wilson (2008) Alaska	Participants age range 18 to 59. Caregivers (n=81), parent (n=3) both parent and carer (n=2) and unknown (n=1)	160 caregivers within three agencies that provide services to people with ID in Anchorage. 85 provided feedback that was used.	Perception of Sexuality Scale (POS). Demographic questionnaire.	Significant relationship between attitude of sexual behaviour of the ID population and perceived ability of caregiver to participate in sex education program. Caregivers were uncertain of appropriateness of sexual behaviours in individuals with ID.	Impact of attitudes upon the implementation of sex education programmes
Swango-Wilson (2011) Alaska	Adults with ID based upon AAMR definition and verbally able.	No further participant details	Descriptive inquiry approach via interview for the study. Explored meanings and expectations of	Participants highlighted a lack of sex education programme. Identified three themes that were needed in	Sex Education Programme (Intellectual & Developmental Disabilities)

	Chosen from the self-advocacy group <i>People First.</i>		sex education programmes and the needs of individuals with ID	programmes: development of friendships, development of lasting relationships and marriage, and safe intimacy.	Impact of attitudes upon the implementation of sex education programmes
Yacoub & Hall (2008) UK	Adults with ID recruited via healthcare and social work professionals. Participants came from community settings and secure hospitals	10 participants from community setting (8 own tenancy, 2 residential) age range=29-65; 7 participants from secure hospitals age range 19-49	Semi-structured interviews informed by SexKen-ID	Community based participants more likely to want to be single. General difficulties relating to the social side of sexuality and experiences. Use of contraception and safe sex varied and depended upon coercion.	Sex Education Programme (Intellectual & Developmental Disabilities) Impact of attitudes upon the implementation of sex education programmes

3.3.4 Results

The final focus of the analysis of the relevant studies identified a number of issues:

- The implementation of sex education programmes with students who have IDD, autistic spectrum condition or Asperger's Syndrome
- The evaluation processes used in sex education programmes for students who have IDD, autistic spectrum condition or Asperger's Syndrome
- The issues relating to the attitude of people involved
- The possibility that appropriate SRE may have an impact upon the occurrence of sexual abuse and offending issues
- Issues relating to people with autistic spectrum condition or Asperger's Syndrome, and how this can be managed.

NVivo 10 software was used to organise and identify four primary themes within the chosen articles:

- **Sex Education Programmes (IDD General)**
 - The need for sex education for individuals with intellectual and developmental disabilities
 - Resources available
- **Impact of attitudes upon the implementation of sex education programmes**
 - Individuals with intellectual and developmental disabilities/autistic spectrum condition/Asperger's Syndrome
 - Parental attitude
 - Professional attitude
- **Specific impact of autistic spectrum condition/Asperger's Syndrome on sex education Programmes**
 - Specific related difficulties
 - Need for adaptation to programme and/or teaching methods

In relation to the data obtained for the primary themes, the following outlines the specifics in relation to methodology and background.

3.3.4.1 Sex Education Programme (IDD General)

All except five of the studies provided some form of insight into the implementation of sex education programmes in relation to intellectual and developmental disabilities in general. The countries of origin were varied and included nine from the UK, five from USA, three from Australia, three from the Netherlands, two from Canada, two from Poland, one joint study between Japan and Sweden, and one each from, Sweden, Japan, South Africa and Turkey. The range of methods used to explore this area was nearly evenly spread with eight utilising comparisons between study and control groups participating in sex education programmes, or comparison of knowledge between pre and post intervention, nine utilising self-completing surveys primarily for parents and professionals, and eleven using interviews to obtain data. In the case of the latter two methods, two thirds used tools that were developed explicitly for the specific research, although many were based upon other tools. In these cases, the majority of studies tested the tools in pilot studies prior to the main study. This

could bring into question the reliability of the tools as frequently the pilot studies were small involving 10 or fewer participants.

The need for effective sex education for individuals with IDD is not purely about imparting knowledge but also to reduce the individual's vulnerability to abuse by developing their understanding in regards to their capacity to consent. Although some studies (Lumley & Miltenberger, 1997) argue that the knowledge does not necessarily translate into the individual being able to protect themselves effectively from abuse and coercion. Additionally, the increase in sexual knowledge can potentially reduce the possibility for the individual to come into contact with the Criminal Justice System due to their increased understanding about the socio-sexual boundaries. However, as previously discussed, this can contradict the perception by some about the possibility of how the teaching of sex education with individuals with intellectual and developmental disabilities can potentially increase the possibility of deviant sexual behaviour being displayed. Dukes and McGuire's small study (2009) provided some evidence in relation to increased capacity to consent and suggested that capacity to consent was not static but could be improved through the use of an appropriate, individualised sex education programme. Although this is an important concept to consider, it must be recognised that this study was based upon four case studies. However, further reinforcement came from Kijak's Polish based study (2013) involving individuals with intellectual and developmental disabilities using interview questionnaires and associated visual materials. The results indicated that many of the participants possessed the appropriate sexual knowledge but had great difficulty in understanding the more abstract social sexual issues which were too abstract and fluid in nature. This was further highlighted in an American study utilising a curriculum that had been previously developed and used with a group of adults with intellectual and developmental disabilities in a University based environment (Graff et al, 2018). This study involved the use of pre, and post assessment tools developed specifically for the study, and a structured sex education programme which included five chapters:

1. relationships and self-awareness.
2. Maturation
3. The life cycle
4. Sexual health

5. Being strong, staying safe.

The group involved were older than many other studies with mean ages of participants being over 20 years. Although the programme had been targeted at individuals with intellectual and developmental disabilities, the results indicated that there were difficulties in providing all the relevant information. This led to the results indicating that many participants found it difficult to implement the socio-sexual knowledge in practice. In addition, there are issues connected to the sex education programmes being implemented within schools. The aim of such programmes should be the empowerment of the person to be able to safely develop sexually, as well as provide an open forum to discuss such issues (Murphy & Young, 2005). The difficulties surrounding the acquisition of sexual knowledge via education within the national curriculum based SRE programme was recently highlighted within the mainstream media. The article in the national Guardian newspaper (Fitzherbert, 2014) examined the difficulties faced by individuals with a range of disabilities in accessing appropriate sex education. The article highlighted how many individuals with disabilities are neglected in the area of sex education. According to the source study (Cheshire Report, 2010) generally the percentage of disabled people that did not receive sex education was almost half (44.5%) regardless of whether they were attending mainstream or special school. Further investigation into the situation showed how this has been the situation for many years, and that there is also a significant difference between those with physical disability and those with intellectual and developmental disability, with the former group receiving a greater amount of sex education than the latter group (McCabe, 1999). In an earlier study (Ruble & Dalrymple, 1993) it was reported by a group of parents that the probability of their child receiving sex education increased the more verbally able the child was. However, when Stokes and Kaur (2005) asked a similar question to a group of parents of adolescents with high functioning autism and good verbal communication, the results indicated that the occurrence of sex education was still less than their neuro-typical counterparts. Similar results were obtained by a study in Turkey (Isler et al, 2009) which attempted to explore various attitudes and development in a group of 60 disabled students aged between 15 and 20 years attending an occupational school in Turkey that accepted students with mild or moderate ID who had completed elementary education. The results of the questionnaire completed by each participant indicated that over half (51.7%) reported that they had not received any formal sex education. However, when examining these results, it is important to place them in context in relation to cultural aspects of Turkey, particularly those relating to the Islamic faith which is

prominent in the country. In a society where gender inequalities, rigid gender roles exist and discrimination against the lesbian, gay, bisexual and transgender community persists, the possibilities of a comprehensive sex education that incorporates the necessary scope of information are limited (Aras et al, 2007). Consequently, in the absence of information in 46.7% of the individuals involved with the study, the adolescents identified that their alternative sources of knowledge were primarily information from friends, the media and the internet, all of which frequently provide misinformation on the subject which the person with intellectual and developmental disabilities is left to interpret and then utilise in an appropriate fashion. This is further affected by the individual with disability being less likely to check and discuss the accuracy of any information they have obtained with more reliable sources (McCabe, 1999). The consequence of such a lack of appropriate sex education becomes even more apparent when studies have shown that over a quarter (28%) of teenage mothers have additional learning disabilities and that a review of data obtained from a special needs school in the same study showed that 40% of female pupils with some form of intellectual and developmental disabilities had become pregnant within 18 months of leaving school (Heer, 2008). Even in cases where sex education has been shown to improve areas of knowledge, such as contraceptive knowledge (Lindsay et al, 1992), there have been indications that this is still not enough. One study's data (Yacoub & Hall, 2008) indicated that amongst a group of men with mild intellectual and developmental disabilities living in either community setting or secure hospital setting, it was important for professionals to not make assumptions about knowledge acquisition. Therefore, the study highlighted the need to ascertain both the level of knowledge gained by the individual with intellectual and developmental disabilities through the sex education programme as well as how the knowledge had been put into practice by the individuals.

In relation to the specifics of sex education programmes, in the UK the national curriculum (Department of Education, 2014) outlines the teaching structure and content. However, as mentioned in a previous section, individuals with intellectual and developmental disabilities or autistic spectrum condition require additional support which primarily centres upon the wider aspects of sex and sexuality, including the wider social arena. Although the generic sex education programme covers a range of topics, when performed with individuals with IDD there are often gaps in the process and information provided. Isler et al's study (2009) found that even when in receipt of a sex education programme, a huge proportion of individuals still had shortfalls in their basic

knowledge. Further studies (Swango-Wilson, 2011; McGillivray, 1999; Lindsay et al, 1992) also discussed such deficits in knowledge, particularly in relation to the sexual act and consequences of sexual intercourse. This may have origins in society's reluctance, including professionals and families, to discuss the sexual behaviour of those with disabilities (Isler et al, 2009). Such attitude and belief issues will be explored further later in the review.

As well as the factual aspect of sex education, many studies have highlighted the lack of discussion surrounding the more abstract issues of sexual based social skills. These frequently involve issues relating to relationships, friendships and associated intimacy (Swango-Wilson, 2011). The issue of relationships knowledge also proved difficult in the Graff et al (2018) study within which some of the participants were enthusiastic to talk about such issues due to their interactions with other participants, including developing 'crushes'. However, they found the concepts of safe relationships difficult to deal with even though this had been discussed within the curriculum. The need for such social skills development is reflected in the vulnerability to sexual abuse of adolescents with intellectual and developmental disabilities. Although possessing an appropriate level of social skills does not guarantee that an individual with intellectual and developmental disabilities will not be abused, it can help improve the judgement of an adolescent with intellectual and developmental disabilities when confronted with a potentially abusive situation (Isler et al, 2009). In the case of 17 individuals with intellectual and developmental disabilities who participated in a social skills based sex education programme in Japan, the scores relating to this area increased, although there were still practical issues which were linked with the high ability of participants which means that any future research should concentrate upon those individuals with intellectual and developmental disabilities who possess less ability. Also, there were concerns relating to the interactions and influences that may have occurred within the group and impact upon the results. Finally, the study authors felt that as the programme was developed within the Japanese culture, it would not be transferable to other cultures (Hayashi et al, 2011).

In relation to the actual implementation of sex education programmes this is often left to the schools to plan, particularly within the UK National Curriculum, and frequently led by a designated member of staff with an enthusiasm for the topic who will attempt to cover all aspect of SRE. However, this can be restricted by rules and regulations of the specific establishment which may limit what the

individual can do, or feel supported to do (Lafferty et al, 2012). Also, often the individual staff leading the SRE programme has not been specifically trained in delivering sex education even though they are expected to deliver it. Consequently, these situations often result in the involvement of external agencies to deliver specific aspects of the SRE curriculum, which can reduce the involvement to “one-off” visits rather than a structured programme which provides consistency for individuals in receipt of it.

Alongside training issues sits availability of resources. The difficulty in accessing appropriate sex education resources relates to the lack of understanding in relation to each programme, how they are developed and evaluated (Schaafsma et al, 2013). Although Schaafsma et al’s study attempted to look at the development of a number of sex education programmes (five in total), unlike some sex education packages such as Sex and the 3Rs programme (McCarthy & Thompson, 2008), the programmes identified seem to not be formal, but were more situation specific involving a number of individual approaches. However, the study did identify a range of stages in the development of programmes. These were:

1. Needs assessment
2. Outcome measures
3. Theoretical basis of programme
4. Involvement of the target group
5. Evaluation

Unfortunately, although these stages were identified, there was no consistency amongst the five programmes in regards to the implementation of the first three stages. The last two stages did produce consistent results but only because none of the five programmes actively involved the target group in its planning due to time (stage 4), and no evaluation concerning the process and materials involved occurred in any of the programmes reviewed (stage 5).

Overall within the systematic literature review, only two studies specifically examined the practical aspects, e.g. materials and teaching methods. One (Newens & McEwans, 1995) compared two group

sessions, one in a school and one in a community setting. The results were mixed in nature as it was felt that the school session was more beneficial due to the already developed relationship between teacher and students. However, the community setting, although not as successful, did prove beneficial in terms of knowledge acquisition, but this may have been due to some previous teaching for some of the participants. Generally, the study seems to indicate that the materials used were not a deciding factor, but it was more the explorative discussions that subsequently occurred which improved outcomes. The second study (Haight et al, 2001) was small in nature (six students with intellectual and developmental disabilities along with six “average” students) and utilised a formal approach, *Sexuality, Love and Maturity* worktext, to dictate the course content and materials. The results indicated that knowledge surrounding a number of human sexuality concepts, including relationships and some aspects of love, improved, but it is unclear whether this was due to the material used or the influence of the “average” students. Although another study (Graff et al, 2018) did not explicitly explore the practical aspects involved with sex education programmes, it did highlight that there had been some difficulties in the programme that had been used. Although the programme had been specifically developed for individuals with intellectual disabilities, it was recognised that further adaptation was necessary due to the wide range of abilities, particularly reading levels, that were present amongst participants. This was similar to the study by Hayashi et al (2011).

3.3.4.2 Impact of attitudes upon the implementation of sex education programmes

In relation to the issue of attitudes, all except two studies (Rohleder, 2010; Lindsay et al, 1992) looked at this area in some way. The issue of attitude can be problematic to explore especially in relation to a sensitive topic such as sexuality and sex education for people with intellectual and developmental disabilities, autistic spectrum condition or Asperger’s Syndrome. As previously discussed, it is only in recent decades that such areas have been more openly considered by everyone involved in supporting these groups of people. In addition, there are potential pitfalls in the attitudinal development of an individual with intellectual and developmental disabilities, autistic spectrum condition or Asperger’s Syndrome depending upon their upbringing, their age and religious background, as well as the influences of those supporting them. The latter is important to consider

as some of the UK based studies were done within Northern Ireland where religious views of those supporting people with ID may impact upon the individual's attitude toward sexuality in this group of people. Finally, it is important to note that previous studies (Dilorio et al, 2003) showed that adolescents with IDD would discuss sexual matters mostly with their mother rather than their father, which could provide some form of bias in relation to study results.

Generally, the methodology used for exploring attitudes centred upon either surveys or face to face interviews, although group interviews were performed with some of the participants with intellectual and developmental disabilities, autistic spectrum condition or Asperger's Syndrome. As with the Sex Education Programme aspect, many of these measures were developed explicitly for the study with some being based upon previous tools. This was especially true when the participants had intellectual and developmental disabilities, autistic spectrum condition or Asperger's Syndrome and it was felt necessary by the researchers to make relevant changes to make it more accessible. As highlighted in Chapter Two, much of the literature reviewed explored attitude issues regarding people with intellectual disabilities perhaps because of autistic spectrum condition only becoming more widely recognised in recent years. The review results further reinforced the concern described in the previous chapter, held by the general population, including parents, caregivers and professionals that people with intellectual disabilities could, in any way, require sex education. With regard to the parental aspect, this often centred upon a need to protect their child from the influence of society and the concerns that discussion surrounding sexual relationships were either irrelevant for their child due to perceived ability levels or would make the individual vulnerable to potential abuse. In contrast, many of the staff attitude difficulties seemed to be centred upon concerns that professionals did not have the knowledge or skills to provide appropriate support and education. This perceived lack of skills was then felt by some as a potential difficulty for professionals who feared that they might face complaints and disciplinary processes due to not teaching individuals with intellectual disabilities appropriately.

In relation to the issue of attitude toward sexuality and sex education, a range of studies have explored the perceptions of people with intellectual and developmental disabilities. Frequently these have demonstrated that a conservative view in relation to sexual issues is also present in people with intellectual and developmental disabilities (Lunsky & Konstantareas, 1998; Timmers, DuCharme, &

Jacob, 1981). In one particular study utilising a 31 question interview with secondary students aged 14 to 17 years with mild intellectual and developmental disabilities, (Brantlinger, 1983) the majority (10 out of 13) of the students felt that sex was “dirty and nasty”. This attitude toward sex was often reported within the interviews as being due to participants being taught and encouraged to not talk about sex. However only 3 (24%) of the students disapproved of sex before marriage. When the latter issue was considered in the study by Isler et al (2009) via the use of a questionnaire completed by each participant, out of 60 students aged 15 or over, just under 50% ($n=28$) disapproved of sex before marriage with nearly two thirds of them being boys. As previously highlighted, this study was performed in Turkey where the religious and cultural views in relation to sex education has impacted upon the level of sex education provided. Within the same study information was obtained in relation to the pupils’ attitude toward masturbation, including participation in such activities, and the levels of masturbation. Within the results, 8 of the participants (1 girl, 7 boys) felt that only boys masturbated, when questions were asked concerning levels of shame relating to masturbation only 3 participants, all boys, felt it was a shameful act. This low rate contradicts another study (Kijak, 2009) which found that 76% of 17-20 year olds with moderate intellectual and developmental disabilities admitted to masturbating. This was felt by the study researcher to be due to the tendency for such youth to avoid engagement in more social based sexual activity such as necking, petting or first sexual contact. Therefore, masturbation provided individuals with the sexual relief they were seeking. Some of this can be due to underlying issues relating to a person’s diagnosis, such as a lack of social skills required to initiate and maintain an appropriate intimate relationship. Also, there were issues related to participants’ abilities in using “sexual scripts” (Gagnon et al, 1973). Such sexual scripts go beyond normal social skills and aim to provide a person with guidance as to the processes involved in such contact whilst keeping those involved safe but tend to be as fluid and vague as general social scripts. This lack of sexual knowledge and experience impacting upon an individual’s attitude was explored by Dukes and McGuire (2009). Within their limited study, they utilised educational interventions as a way to enable four people with intellectual and developmental disabilities to make more informed sexuality-related decisions. By using a single subject design involving multiple baselines, the study demonstrated improvement and maintenance of knowledge surrounding keeping safe, whilst general sexual knowledge slightly decayed but still remained high. Of course, this was a small scale study, but does provide some insight into the benefits of sex education for individuals with intellectual and developmental disabilities.

Further discussion surrounding knowledge, especially in relation to the law was considered in O'Callaghan & Murphy (2007) who demonstrated how a group of adults with IDD (mean age of 37.6 years) possessed limited understanding in relation to the legal aspects of their sexuality and sexual relationships, compared to neurotypical individuals. This lack of understanding was present throughout the relevant studies with indications by some (Swango-Wilson, 2011; Dukes & McGuire, 2009; Isler et al, 2009) that this deficit further impacts upon the attitude of the individual with intellectual and developmental disabilities toward their own sexuality. However, this may also be due to a lack of appropriate teaching which provides all appropriate information and allows for any necessary modification in attitudes and values (Newens & McEwan, 1995). Such support enables the individual to achieve their basic human rights to experience emotions and sexual urges (Swango-Wilson, 2011). Further exploration by Lunsky et al (2007) into the conservative view of sexuality by people with intellectual and developmental disabilities, highlighted differences in attitude between two types of sex offenders with intellectual and developmental disabilities: Type 1 who are on par with their mainstream counterparts, and Type II who commit sexually inappropriate offences but these are seen as more "minor or nuisance offences" (Day, 1997). The results of Lunsky et al's study showed that the attitude toward one particular area: same-sex relationships, were less conservative in Type I offenders in comparison to the more conservative view of the Type II offenders and the matched sample of non-offender group. Once again it is theorised that this difference has some connections with sexual knowledge and experience received.

Although formal sex education originates mostly from schools, the ability to use the skills and knowledge obtained is often reliant upon the social opportunities provided outside the learning environment by parents and carers. This is especially true as the young person with intellectual and developmental disabilities attempts to develop their social and sexual independence. In comparison to their neuro-typical counterparts, teenagers with intellectual and developmental disabilities often require greater amounts of assistance and supervision rather than being allowed to develop their skills and knowledge naturally (Cole & Cole, 1993). This often places them at risk from becoming socially isolated and so having fewer opportunities to mix and learn from their peers (Isler et al, 2009). Consequently, it has been thought that this isolation from their peers reduces the opportunity to

develop their sexuality, as well as engaging in social and sexual experiences (Berman et al, 1999). Unfortunately, without such experience, adolescents with intellectual and developmental disabilities are often excluded from developing the experiential side of sex education and sexual development. This lack of opportunity has been demonstrated to be a potential contributing factor toward limited level of sexual knowledge demonstrated by some adolescents with IDD (Cheng & Udry, 2003; Isler et al, 2009; Pownall, 2010; Szollos & McCabe, 1995). This reliance upon others then impacts upon the experiential side of sex-related matters; both due to the practical aspect as well as the attitude of others, mostly parents and carers.

The need for parental involvement in providing appropriate sex education, specifically around relationships, has been shown to be of high importance in any teenager's development (Pownall et al, 2012). However, as highlighted by a number of studies (McCabe, 1999; Pownall, 2010), often the range of topics discussed between parents and teenagers with intellectual and developmental disabilities can be limited. Pownall et al's study involving two groups (60 in total; 30 intellectual and developmental disabilities, 30 non-intellectual and developmental disabilities), explored the level of sex education performed by, in this instance, mothers. The results demonstrated how those mothers with adolescents who had intellectual and developmental disabilities were more liable to discuss fewer sexual based topics than mothers with non-intellectual and developmental disabilities adolescents. In fact, the emphasis by this parental group of teens with intellectual and developmental disabilities centred very much upon issues surrounding keeping sexually safe rather than the greater sexual knowledge provided by parents of non-intellectual and developmental disabilities teenagers. This reinforced earlier results from Ruble and Dalrymple's study in 1993 which illustrated how two thirds of parents of females with intellectual and developmental disabilities were concerned about their daughter getting pregnant whilst only a fifth of parents of males with intellectual and developmental disabilities were concerned their son would get someone pregnant. However, these latter parents were more likely to be concerned about same-sex abuse, whereas parents of females with intellectual and developmental disabilities were more concerned about their daughter being taken advantage of by the opposite sex. Similar results were found in relation to such issues in Stokes and Kaur's study (2005) which indicated that as the adolescent grew older, so the parental concerns grew. Pownall et al also provided indications that mothers of adolescents with intellectual and developmental disabilities waited longer before imparting information than those

with non-IDD teenagers, especially when the teenager was a girl. In an earlier study (Katoda, 1993) it seemed that the issue of discussion between parent and adolescent can also be affected by cultural issues. When parents in Tokyo and Stockholm were asked if they had discussed such topics with their child, a huge proportion of the latter group (95%) said yes, whilst of the former only 65% said yes. Within the study, the researchers speculated that this difference was due to the differing cultures involved with the study and associated views on sex education.

The emphasis upon being sexually safe often seems based upon, not just the parents' own belief, but also upon a history of inappropriate sexualised behaviour that may have been demonstrated by their child (Stokes & Kaur, 2005). Ruble and Dalrymple (1993) found that 61% of individuals with autistic spectrum condition had engaged in such behaviour or had engaged in behaviour that could be misunderstood as sexual. This view was reflected in Katoda's study (1993) involving parents from Tokyo. In general, studies have demonstrated how the attitudes of parents with teenagers who have intellectual and developmental disabilities are seemingly in contradiction. Consistently studies have demonstrated how parental attitudes toward the sex education of teenagers with intellectual and developmental disabilities highlight constant battles between the recognised need for education in such areas whilst simultaneously ensuring the safety from sexual abuse or exploitation of the adolescent or adult with intellectual and developmental disabilities. More specifically studies such as Cuskelly and Bryde (2004) have demonstrated how parental age was an important influencing factor in relation to the attitude toward the sexuality of individuals with intellectual and developmental disabilities. The study utilised three sets of participants in the form of parents, support staff and general public, all with a wide age range, except for the parents who were all aged from 41 years. Even with this imbalance the results indicated that attitude toward the issue of sexuality and intellectual and developmental disabilities became less liberal the older a person was. Additionally, the attitude of parents also changed depending upon the levels of sexual behaviour exhibited by the individual with intellectual and developmental disabilities. The more sexually intimate the behaviour exhibited by an individual with intellectual and developmental disabilities the greater the disapproval and concern was exhibited by the parents (McCabe, 1993).

With much of the teaching of SRE coming from staff, the perception and views of the professionals involved with sex education and people with intellectual and developmental disabilities can often have a massive impact upon the situation. Parchomiuk (2012) found that groups of professionals in Poland were more positive about individuals with physical disabilities receiving sex education than their intellectual and developmental disabilities counterparts, and this did depend upon the professional's background, although they all had connections to individuals with disabilities. Also the individual professional's belief system, whether religious (Ryan & McConkey, 2000), cultural (Katoda, 1993) or upbringing-based can also have an effect upon how sex education is provided to people with intellectual and developmental disabilities, although this can be in a positive way too (Brown & Pirtle, 2008). Swango-Wilson (2008) explored the connection between the attitude of professionals and the issue of sex education through 87 participants who worked with individuals with intellectual and developmental disabilities. This showed that participants felt positive about individuals with intellectual and developmental disabilities and their ability and need for sex education, but the perception of professionals in relation to the appropriateness of sexual behaviour displayed by individuals with intellectual and developmental disabilities was less clear. Graff et al (2018) also explored the attitude of carers, specifically paid carers, concerning their views of sex education and individuals with intellectual disabilities. Although, as with Swango-Wilson, there was a positive attitude concerning the need for sex education for people with intellectual and developmental disabilities this was not always the case. For a number of the 163 paid carers participating in the study, when focussed upon the specific clients they supported, the study highlighted a number of comments stating that the clients did not need to know about sexual aspects of life. This view was frequently expressed as the carer believing that the clients did not want to be educated or were not sexually active, although there were no indications that the clients had actually been consulted about their needs. This often came from the younger paid carers and often resulted in sex education only being taught in a reactive manner when something had occurred, such as the display of inappropriate sexualised behaviour or a client asking sexually related questions. The recognition in relation to the need for sex education continued throughout other studies (Lafferty et al, 2012) within which issues arose such as the increased community opportunities that were available for individuals with intellectual and developmental disabilities and/or autistic spectrum condition resulting in the need for sex education. Lafferty et al also highlighted four main barriers that reinforce much of what has been discussed within this chapter:

1. Protection versus personal development
2. Lack of training
3. Scarcity of education resources
4. Cultural prohibitions.

Frequently studies have demonstrated how even professionals entrusted with the implementation of either the education or counselling on sexuality issues have their own high anxiety about performing such tasks (Parritt & O'Callaghan, 2000). Often this has been based upon the unfounded belief that the teaching of such issues could encourage the person with intellectual and developmental disabilities to engage in inappropriate sexualised behaviour (Rohleder, 2010). This anxiety is contradicted by the previously identified need to encourage safety in people with intellectual and developmental disabilities, especially in the area of abuse and contracting sexually transmitted infections, particularly HIV/AIDS (Rohleder & Swartz, 2009). Consequently, for many professionals, the need for appropriate organisational policies and procedures to protect both the individual with intellectual and developmental disabilities and the professional is imperative in dealing with these barriers but are often not present. Unfortunately, the resulting lack of appropriate support for individuals with intellectual and developmental disabilities had been recognised in one study within which half of participants (adolescents with intellectual and developmental disabilities) felt that professionals had not provided them with any form of sex education (Isler et al, 2009).

3.3.4.3 Specific impact of autistic spectrum condition/Asperger's Syndrome on sex education programmes

Studies relating to autistic spectrum condition and sex education were sparse which was highlighted within one of the studies (Dekker et al, 2015). Consequently, only four studies met the specific search criteria. All except one (Ruble & Dalrymple, 1993) were written post 2000, although the 1993 study was frequently cited in a number of the literature reviews found and in one of the studies (Stokes and Kaur, 2005).

Of the four studies, one was from Australia (Stokes & Kaur, 2005), one from the Netherlands (Dekker et al, 2015), one from UK (Hatton & Tector, 2010), and one from USA (Ruble & Dalrymple, 1993). Both the Australian and USA studies utilised surveys with parents of children/teenagers with autistic spectrum condition. In both cases, the surveys were closely linked, as the later study (Stokes & Kaur, 2005) developed their Sexual Behaviour Scale (SBS), based upon the Sexuality Awareness Scale (SAS) developed for the Ruble and Dalrymple study (using a pilot sample of 10 parents). Although the SBS was an adaptation of the SAS, it does provide some insight into any development that may have occurred between the two studies. The groups of individuals with autistic spectrum condition were similar in relation to distribution of females and males, and the number of surveys completed were substantial in both studies (100 for Ruble & Dalrymple, 150 for Stokes and Kaur). The third study (Hatton & Tector, 2010), in a single school, took a different approach and utilised discussion groups (for n=12) and semi-structured interviews (for n=4) with people with autistic spectrum condition. Consequently, this brings into question whether the study's results can be generalised as it only examined a small group of individuals within one specific school. In addition, two follow up evaluations of the developed curriculum (4 months later and one year later) centred more upon staff interpretation and views of the curriculum rather than as a follow up with the individuals who took part in the original study. The final study (Dekker et al, 2015) examined the results of a pilot study utilising a programme developed for the study. The Tackling Teenage Training program included 18 one-hour sessions which explored a range of psychosexual areas, including sexual behaviour and sexual socialisation. The pilot group consisted of 30 11-19 years olds all with Autistic Spectrum Condition. The majority of participants were male and either attended an inpatient or outpatient clinic in the south west Netherlands. Each participant was assessed pre and post intervention utilising an adapted version of a Dutch high school biology test relating to sexual knowledge. The results of the study showed an increase in knowledge following the intervention being implemented. However, there was some discussion surrounding how the level of improvement was potentially linked with both the age and ability level of the participants at the start of the program.

As previously mentioned, in this thesis, it is recognised that sexuality and sex education can potentially be affected by aspects of autistic spectrum condition. The four studies that were reviewed all used this as a basis for their hypotheses, although Stokes and Kaur (2005) study concentrated upon this most in their study of a group of adolescents with high functioning autism (HFA) who were found

to have poorer social behaviours than their neuro-typical counterparts. This study also highlighted how the participants with HFA also engaged in more inappropriate sexual behaviours whilst possessing less knowledge and practical understanding relating to privacy.

Unlike in the realm of intellectual and developmental disabilities, SRE programmes for people with autistic spectrum condition have not received much focus until recently. Within the present literature review, the number of relevant studies was only 10% of the total studies accessed for the overall review. Even within one of the studies (Dekker et al, 2015), it was highlighted that there was a distinct lack of evidence-based sex education programs available for individuals with autistic spectrum condition. The available studies emphasised how the present method of implementing an SRE programme is frequently inadequate for people with autistic spectrum condition or Asperger's Syndrome. This is especially true in relation to those individuals with Asperger's Syndrome or high functioning Autism who attend mainstream schools. Within these situations often SRE is delivered in large groups of pupils with very little time for questioning and with material that has not been appropriately adapted to the needs of pupils with autistic spectrum condition. In addition, feedback from sexual health staff to the present writer has illustrated how teaching students with autistic spectrum condition or Asperger's Syndrome in large mainstream classes reduces the ability to provide time for detailed exploration and clarification for those who need it, specifically those with autistic spectrum condition or Asperger's Syndrome. In turn this raises concerns about whether the student with autistic spectrum condition and Asperger's Syndrome fully develops the knowledge and skills needed to understand their sexuality and sexual needs which will help to keep them safe.

When examining the specifics such as the issue of social behaviour, especially when associated with sexual situations, two of the more recent studies provided both qualitative and quantitative data in support of its impact. The results indicated that there is considerable difference between social skills of adolescents with autistic spectrum condition and their neurotypical peers. This seems related to delayed development which occurs, with one study (Stokes and Kaur, 2005) finding a five-year delay in the development of social skills of adolescents with autistic spectrum condition. This was further

reinforced by comments made by adolescents with autistic spectrum condition when asked their opinion in Hatton and Tector (2010):

“It would have been helpful to have learnt about how to make friends, to learn what people are interested in and how to have conversation.”

Hatton & Tector, 2010

When looking at specific aspects of this development, only one study (Stokes & Kaur, 2005) explored whether there were differences within the range of autistic spectrum condition. The evidence, although limited, showed that within the autistic spectrum there is very little difference between those with more severe autism and those with high functioning autism in relation to the impact of age and issues with social skills. Throughout the studies reviewed there was agreement that the topic of social skills in relation to sex education was imperative for individuals with autistic spectrum condition. Although sex education typically explores the mechanics of sexual relationships, the results indicate a need to provide individuals with autistic spectrum condition with a foundation of knowledge concerning issues such as how relationships work. In one case, such a deficit prevented one interviewee from having insight into her own social and sexual behaviour resulting in her becoming sexually promiscuous due to her perception that this was how to have a relationship.

Inappropriate sexual behaviour was a common discussion within all four studies, and all identified that adolescents with autistic spectrum condition displayed more inappropriate sexual behaviour including public masturbation, touching private body parts in public and speaking about sexual acts. These difficulties were also found in relation to privacy issues. This was found to not be reliant upon gender, which was only an issue when it came to parental perceptions demonstrating that parents of boys with autistic spectrum condition were more concerned about the behaviour being displayed (Ruble & Dalrymple, 1993). Once again, as with social aspects, age and development when compared to neurotypical adolescents was a primary factor in the development of such behaviour. Of course, underlying all of these difficulties is the need for appropriate knowledge for those with autistic

spectrum condition. In interviews (Hatton & Tector, 2010) all respondents expressed a need for more information relating to sex education, more specifically relationships and social aspects of life.

When focussing upon the issue of teaching materials, the evidence for adaptation is based upon the specific issues previously discussed. The results of the Ruble and Dalrymple (1993) study highlighted how a high proportion of parents (between 86% and 97%) identified the need for present sex education to be adapted in order to take into account the processing issues present in their children with autistic spectrum condition. The program developed for the Dekker et al (2015) study explored these issues and was based upon attempting to overcome some of the difficulties. Hatton and Tector's (2010) examination of the curriculum for pupils with autistic spectrum condition or Asperger's Syndrome, although useful in understanding the difficulties in teaching this group of pupils and the need for curriculum adaptation, was limited regarding the sample size. This sample was obtained from a number of pupils within the school, and although it backed up some of the concepts surrounding the need for adaptation originally identified, it cannot necessarily be generalised across a wider area. However, even with such limited data, some of the qualitative data obtained in the form of participant comments highlighted some of the shortfalls in the curriculum including:

*"I get into trouble sometimes because I can't read the signs, when to talk and when not to."
(P.71)*

"I wish I had learnt to keep myself safe and what is meant if someone asks you to go for a walk and then they want to touch you – I did not understand." (P. 71)

In addition to Hatton and Tector, there continue to be other examples across schools (Speirs, 2006) that there are failings in the current sex education curriculum and material being used with students with autistic spectrum condition or Asperger's Syndrome, which occur despite Government

recognition that the need for pupils with disabilities, including autistic spectrum condition and Asperger's Syndrome should be examined:

“SRE should be inclusive and meet the needs of all young people, recognising that existing SRE provision does not always take sufficient account of issues such as sexuality, disability, ethnicity and faith.”

(Department for Children, Schools and Families, 2008)

3.4 Discussion

This chapter has continued the exploration of how present day SRE programmes have developed. The need for a comprehensive SRE programme for individuals is imperative. It provides the underpinning knowledge and skills to help people develop healthy, intimate relationships and reduce their overall vulnerability. Unfortunately, the progress made in regards to individuals with intellectual and developmental disabilities and/or autistic spectrum condition has been slow compared to the neurotypical population. This has been particularly true for those individuals with autistic spectrum where development in more appropriate SRE programmes has only been considered separate to individuals with intellectual and developmental disabilities in recent years. In relation to this author's experience, much of my work places me in contact with young people who have various special needs including intellectual and developmental disabilities, and/or autistic spectrum condition, as well as working with a number of organisations in implementing sex education programmes with young people with these conditions. Such work has reinforced the results of Dekker et al (2015) study which highlighted the lack of such programmes for individuals with autistic spectrum condition and the need for more to be done within this area. Also, the studies and my own experiences have highlighted issues relating to how such programmes are implemented and their results; both positive and negative, and a perceived difficulty in effectively implementing such programmes. Although a range of approaches have been attempted, along with evaluation methods, those with autistic spectrum condition continue to be at a disadvantage due to specific issues relating to these conditions.

The development of appropriate SRE programmes for individuals with autistic spectrum condition has been rife with outdated perceptions and attitudes. The idea that individuals with autistic spectrum condition possess no desire for any form of relationships, sexual or otherwise, has long been disproved, and yet there are still many professionals that hold on to this belief. Although in some cases, yes, an individual with autistic spectrum condition may not actively seek or desire this, that is their individual preference and not a reflection on the wider community. Also, the perception by some that by opening up the 'can of worms' that is teaching SRE to individuals with autistic spectrum condition, then the chances of that individual displaying some form of inappropriate sexualised behaviour is increased if not guaranteed. However, as has been shown, by not teaching SRE we are potentially increasing the vulnerability of individuals with autistic spectrum condition. Even in the case of an individual with autistic spectrum condition not being able to participate in sexual intercourse due to an additional intellectual and developmental disabilities, is it not their right to understand consent? In this case, these individuals will potentially always receive 24 hour care and support, including intimate care. If we as professionals and a society decide that such individuals do not need to understand just the basic safety aspects (e.g. public/private, good & bad touch, how to indicate "NO"), does this not place the individual in position in which they become silent victims of sexual abuse.

Of course, the responsibility for the shortfall in appropriate SRE programmes should not be entirely placed at the feet of those directly in contact with individuals with autistic spectrum condition. Often the concern about the 'can of worms' is as much about the commitment of organisations to provide the support for all involved with the process. Even where individual professionals and carers have clearly identified the need for SRE programmes, the fear is that a lack of training for staff, policy and legislative concerning SRE places them in a dangerous position. This is especially true in a general climate of blame and compensation that has seeped into every aspect of daily life. Consequently, unless there are individuals who are ready to put their head above the parapet and put themselves on the line in order to provide such programmes, people with autistic spectrum condition are going to have to fumble their way through the SRE minefield alone. The results will be a whole generation

of individuals who are making mistakes that unintentionally overstep the social and legal boundaries leading to knee jerk reactive intervention and a whole list of individuals with autistic spectrum condition being classed as sex offenders for the rest of their lives.

This chapter has discussed a range of difficulties that are faced in helping individuals with autistic spectrum condition, however there has also been the positive move toward providing relevant SRE programmes for this group of individuals. Although development from the point of formal studies has seemingly been slow, behind the scenes there are definite moves forward but more needs to be made of the topic. To assist with identifying positive work in the area of SRE and individuals with autistic spectrum condition the next two subsequent chapter in this thesis will attempt to provide an up to date picture of what is presently being used in educational environments for individuals with autistic spectrum condition. This will include doing something rarely done in this area; gaining feedback from individuals with autistic spectrum condition about their own experiences of SRE programmes and its relevancy.

Chapter Four

STUDY ONE: THE PROVISION OF SEX AND RELATIONSHIP EDUCATION PROGRAMMES FOR INDIVIDUALS WITH AUTISTIC SPECTRUM CONDITION

4.1 INTRODUCTION

A number of studies have examined the issue of sex and relationship programmes, but very few have explored the specifics relating to individuals with Autistic Spectrum Condition. Within the literature review described in Chapter 3, only four of the studies reviewed examined programmes for individuals with Autistic Spectrum Condition.

Within the studies relating to sex education programmes, the majority utilised a knowledge-based approach in their methodology, assessing knowledge by either performing a pre- and post-programme questionnaire to ascertain how much of an impact such programmes have had on the knowledge of the individuals involved or via observations made by others in relation to behaviour changes. In all cases, the studies centred upon a specific sex education programme which was either an established programme; e.g. *Taking Care of Myself* (Wrobel, 2003), or a curriculum developed specifically for that particular study. All except one of the studies reviewed involved the use of control groups in order to strengthen the study's claims about the programme success in developing the knowledge of individuals with intellectual disabilities.

Only four studies (Ruble & Dalrymple, 1993; Stokes & Kaur, 2005; Hatton & Tector, 2010; Graff et al, 2018) attempted to explore the issue of implementation of sex education programmes with individuals who had Autistic Spectrum Condition. The remaining studies involving individuals with autistic spectrum condition primarily utilised face to face interviews with either individuals with intellectual disabilities or individuals with Autistic Spectrum Condition. In all three of these cases, the sample sizes used by the researchers were small (16 with intellectual disabilities, Lofgren-Martenson, 2012; 3 with intellectual disabilities and autistic spectrum condition, Swango-Wilson, 2011; 3 with Autistic Spectrum Condition, Hatton & Tector, 2010). The questioning in all three studies was similar in nature as it attempted to explore the experiences of the interviewees in relation to sex education within schools as well as their perception of what they had learnt. In all cases, these interviews were

done with adults and so relied upon their recollections of their sex education experiences, which may have been some considerable time prior to the study. Consequently, the results could be seen as potentially weak due to the reliance upon an individual's memory and also the small number of participants involved.

In relation to the present study, the primary aim was the exploration of the planning, implementation (including any issues relating to the demographics of the schools) and evaluation of the UK National Curriculum based SRE programmes specifically involving teenagers with Autistic Spectrum Condition, including Asperger's Syndrome, within schools in England. As highlighted within other studies, it has been recognised that an effective sex education programme can improve some of the knowledge and skills of individuals with Autistic Spectrum Condition. Previous research has also shown the benefits of early intervention in the realms of juvenile sex offending, especially in relation to levels of understanding (Vizard et al, 2007). Studies have also reported the way certain deficits in the skills of people with Autistic Spectrum Condition place them in a potentially vulnerable situation (Hayes, 1991; Glaser & Deane, 1999). This frequently centres upon the lack of social understanding and boundaries, which can sometimes result in what is perceived as 'deviant' behaviour leading to misunderstandings from others (Thompson & Brown, 1997; Lindsay, 2002).

A motivator for performing the study was the number of referrals being made to the author, in his role as Special Needs Advisor, relating to individuals with Autistic Spectrum Condition. Despite receiving sex and relationship education within school, these young people were having difficulties in dealing with growing up and all that is involved. In some cases, this had involved contact with the Criminal Justice System due to the individuals' actions.

With this in mind, the overall aim of the study was to ascertain what SRE programmes were being used with individuals with autistic spectrum condition, and whether there was a necessity for any adaptation in order to encompass the areas of difficulties that are recognised as being important for people with Autistic Spectrum Condition to further develop their social and life skills. This need for adaptation of education in general for people with Autistic Spectrum Condition has been recognised

within education provision for many years. Since the beginning of this century, the UK has had an increasing commitment to the principles of inclusion for pupils with any additional needs within mainstream settings (DfES, 2001). As a result, due to the various difficulties experienced by this diverse group, the need to utilise teaching methods and materials beyond the conventional curriculum has to be considered (Whitaker, 2007). This is especially relevant when considering those with Autistic Spectrum Condition for whom such difficulties can increase ongoing stress and anxiety. In relation to the concept of inclusion, although many see the preferable approach as being within mainstream schools, the “Make School Make Sense” Report (NAS, 2006) took a different perspective. The report discussed the need for provisions to provide more person-centred approaches in regard to the curriculum and teaching methods:

“making appropriate provision to meet each child’s needs and reasonable adjustments to enable each child to access the whole life of the school. Every child with autism has different strengths, and a child’s individual needs should be the starting point for identifying what type of school they attend and the support they need in that setting.”

NAS, 2006 p4

Similar views in regards to the needs of pupils with Autistic Spectrum Condition were gained from parents in a range of studies examining inclusion (Kasari et al, 1999; Seery, Davis & Johnson, 2000; Leyser & Kirk, 2004), however very few have explored the issue from the perspective of the pupils with Autistic Spectrum Condition themselves. One study (Whitaker, 2007) utilised questionnaires to parents/carers of children with a formal diagnosis of Autistic Spectrum Condition in the Northamptonshire area, and included mainstream and special needs schools. The responses identified a number of aspects relating to the educational provision for children with Autistic Spectrum Condition, primarily:

- Ensuring that staff have a good, practical understanding of the condition as well as recognising the individual needs of each pupil.

- The need for schools to examine how they encourage pupils with and without Autistic Spectrum Conditions to interact with each other on a social level and to promote the development of relationship skills
- Improved communication between home and school in order to develop more effective relationships between these areas.

The study also recommended two further challenges for schools, particularly mainstream schools which will increasingly be relied upon to provide for pupils with Autistic Spectrum Condition.

- There is a need to develop the skills and knowledge of staff in mainstream schools in order to improve the recognition and support, including additional resources, for pupils with autism related needs.
- The promotion of an inclusive ethos including the flexibility and willingness by staff to develop their understanding and so encourage the inclusive ethos.

In 2002, the “Autism in Schools – Crisis or Challenge?” Report (NAS, 2002) explored the issues relating to pupils with Autistic Spectrum Condition in schools. They found that 1 in 86 pupils had either an Autistic Spectrum Condition which had resulted in the need for additional support, either via a statement of educational need (now known as an Educational, Health and Care Plan) or an Individual Educational Plan within school. When this was split between special schools (e.g. general intellectual and developmental disabilities or autism specific) and mainstream, the ratio of pupils with Autistic Spectrum Condition is 1:3 and 1:128 respectively. When considering the provision for pupils with Autistic Spectrum Condition, the same report broke down the types of school attended by those identified in the survey, which highlighted that nearly a third of children with Autistic Spectrum Condition attended a mainstream school, including accessing a resource centre.

Given the relative lack of knowledge of autism specific sex and relationship education and the likely specific needs of children with autistic spectrum condition conditions, this study aimed to interview

teachers responsible for SRE in schools for children with autism (in both mainstream and special schools) to find out more about their SRE programmes.

4.2 METHOD

4.2.1 Study Aims

Primary Aim:

- Exploration of the planning, implementation (including any issues relating to the demographics of the schools) and evaluation of the UK National Curriculum based SRE programmes involving teenagers with Autistic Spectrum Condition, including Asperger's Syndrome, within schools.

Secondary Aim:

- Consider whether it is necessary to adapt the present SRE programmes used with pupils with Autistic Spectrum Condition in order to encompass the areas of difficulties that are recognised as being important for people with Autistic Spectrum Condition.

4.2.2 Participants

Recruitment of interview participants requires careful consideration to ensure that they are appropriate to the needs of the research. This assists in maximising the strength and relevancy of the information obtained. Consequently, the sampling process must be specific rather than random and can be achieved via a range of strategies (Patton, 1987), dependent upon the individual research aims, especially seeking knowledgeable informants to provide appropriate data. This level of knowledge also relates to the terminology used within the interview to reduce the need for participants to request further information in order to clarify aspects relating to the research aims (Miller & Dingwall, 1997). In addition, in gaining a wide range of relevant views, the ability to test themes that may emerge with new interviewees and choosing appropriate interviewees that enable further development of the results are all essential (Rubin & Rubin, 1995).

An interviewer will gain the best result from participants who feel able to share stories and knowledge whilst also feeling that the interview situation has been a worthwhile experience (Hesse-Biber & Leavy, 2006). This is often encouraged through the confidence gained in the interviewer's skills and fluidity of the interviewing process (Roulston, 2010), as well as their neutrality, thus reducing potential bias and assumptions, which can strengthen the relationship between the participant and interviewer (Curren, 1983). Such a reciprocal relationship reduces any potential hierarchy that can be present in the interactions between professionals and participants whilst also providing strength to explore more sensitive questioning. This is especially true if the interviewer has been able to establish a relaxed and encouraging relationship within which they have provided a sense of trust, reassurance and likeableness (Ackroyd & Hughes, 1992).

The participants for the study were teachers of sex education within schools for teenagers with Autistic Spectrum Condition. The schools that were accessed were ones that provide specific support for students with Autistic Spectrum Condition, identified initially via the government website (www.direct.gov.uk), followed by further confirmation of each school's admission criteria as described on individual websites or recent Ofsted Reports. Consequently, this included special needs schools, schools specifically identified as catering for pupils with Autistic Spectrum Condition and mainstream schools with specialist units for pupils with Autistic Spectrum Condition. Within the specialist schools and specialist units, only those with a minimum of 25% of students with a primary diagnosis of Autistic Spectrum Condition were included. By targeting these specific types of schools, it ensured that there were students with Autistic Spectrum Condition attending, which was imperative for the study. By doing so, the process ensured that many of the students attending the specialist school or specialist unit possessed a primary diagnosis by an appropriate professional of Autistic Spectrum Condition, as identified within their Educational Statement, or the new Education, Health and Care Plan (EHCP).

In addition, the study examined any differences in the SRE programme implementation based upon geographical area, specifically rural and urban communities. Initially the two areas chosen for this

particular study were Sussex and South London, purely for ease of access for the researcher. However, due to a low uptake of participants this was widened to include two further areas: Surrey and North London, both of which were also easily accessed by the researcher.

4.2.3 Measures

The choice of measures for any piece of research is central to the process, along with the practicalities of the implementation. In the case of the present study, there were two processes utilised: online questionnaires in order to ensure that participants met the inclusion criteria and semi-structured interviews to explore the issues in greater detail. Both the online pre-interview questionnaire and the interview schedule were devised specifically for this study.

4.2.3.1 Online Questionnaires

The use of questionnaires, especially in health research, has been popular for some time. The choice of such an approach, especially postal questionnaires, has frequently been based upon the financial viability of collecting large amounts of data from a wide geographical area (Edwards et al, 2002). However, the ability to achieve acceptable response levels in relation to postal questionnaires has been of particular difficulty (Paul et al, 2005)

A previous study was attempted by the present author when exploring the issue of inappropriate sexualised behaviour of teenagers with Autistic Spectrum Condition (as part of an MA in Autism Studies). That study utilised a postal survey (See Appendix A) sent to head teachers of schools catering specifically for pupils with Autistic Spectrum Condition as the primary data collecting method with some telephone follow up. The aim of the study had been to examine the prevalence of inappropriate sexualised behaviour displayed by pupils with Autistic Spectrum Condition. Unfortunately, the study experienced a very low response rate, not uncommon in postal questionnaires (Nakash et al, 2006) (see Fig. 1). There were a range of issues linked to the response rate, including some head teachers apparently not receiving the questionnaire even though it was sent or emailed to the school and potential respondent burden difficulties (Sharp & Frankel, 1983).

A possible way to increase responses centres upon ever developing technology. As the ability to connect to the wider world via the internet increases, so a new avenue for survey completion appears. When such approaches are reinforced by specific survey websites, such as Qualtrics, which also analyse the results and cost less than a postal survey, the use of the internet becomes more attractive. In relation to the present study, it was decided to use an online questionnaire method for initial data (See Appendix B for a copy of the survey) with a follow-up interview, the latter being adopted as a way of obtaining richer data than from a simple questionnaire alone. The online questionnaire contained a combination of questions aimed at obtaining factual information about the school, including approximate percentages in relation to areas such as pupil diagnosis, ethnicity and behaviour.

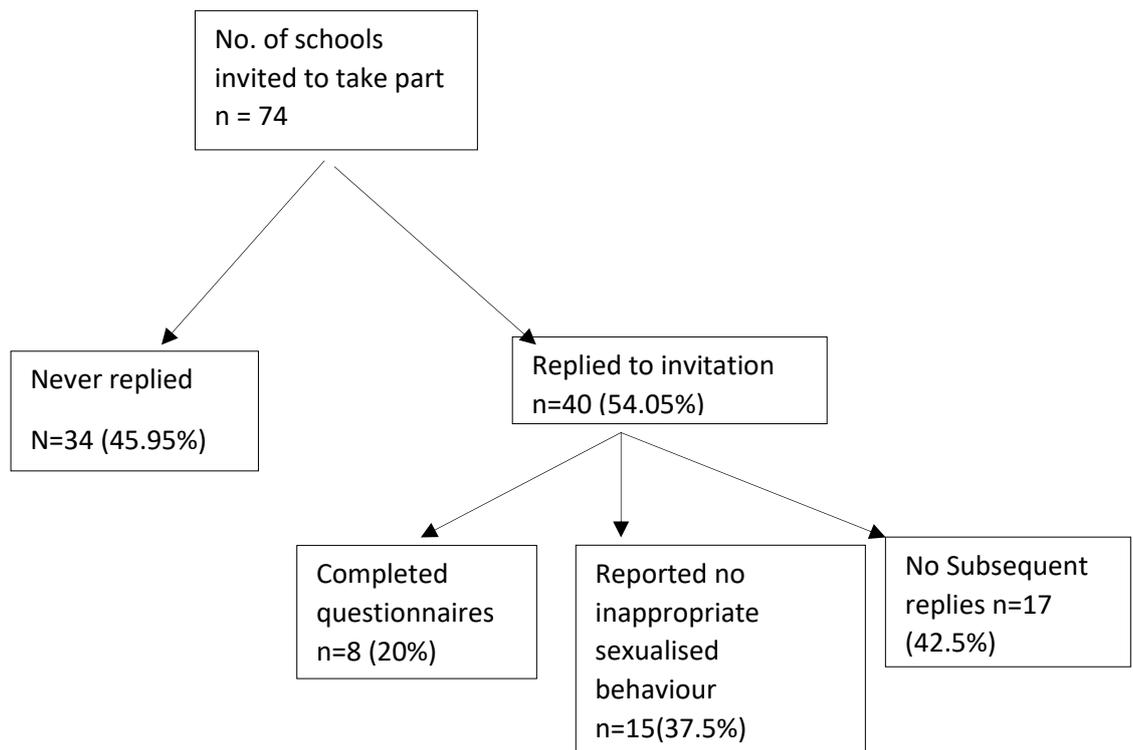


Fig. 4.1 - School response rates in author’s MA dissertation

4.2.3.2 Face to Face Interviews

In the realm of qualitative research, the use of interviewing is one of the primary data collection methods utilised by researchers (Punch, 2005). Interviews can be performed in a range of ways including as a one-off, brief discussion, or as a set of multiple sessions which explore detailed aspects of a person's life and history (Fontana & Fry, 1994). They provide a way to thoroughly explore an area by understanding the perceptions of others within a "listening space" (Miller et al, 1994) where these perceptions can be developed through the interaction between the interviewer and interviewee. Consequently, it is one of the most powerful methods within social science that enables the researcher to gain a greater understanding of the person.

However, using interviews is not simply about compiling a list of questions, but includes a range of factors which the researcher needs to take into account when planning in order to make the interview more effective and productive.

Choosing Interviews

Prior to commencing any form of interview, it is imperative that the researcher understands the distinction between the types of interviews especially the approaches utilised within each one and the subsequent data that can be obtained. There are a number of different types of interviews available, including structured, semi-structured and unstructured, all of which can be utilised for a range of data gathering situations (Punch, 2005). The type of interview chosen can often be dependent upon the researcher's approach to qualitative inquiry and collection.

- Structured interviews involve questioning based upon a set of questions possessing some form of pre-set responses. Such interviews possess little flexibility and variation in the questioning whilst standardisation of the interview is key (Seale et al, 2007).

- Unstructured interviews utilise open-ended questions, providing the interviewer with a wider range of responses. The questions allow greater insight into the thinking and behaviour of people without imposing any pre-defined categories upon participants.
- Semi-structured interviews fall between the two described above, by providing a series of consistent questioning but in an open-ended style. The interviewer can guide the questions to ensure some standardisation, while allowing truly individual and qualitative information to come through.

Interview Preparation

Designing an interview study involves a number of practical considerations to ensure its effectiveness, including selection and recruitment of participants, compiling questions, managing the interview, and how to record the data obtained for transcription.

The development of interviews within social research has been conceptualised by Kvale and Brinkmann (2009) as falling into seven stages:

- Thematising – the why and what of the investigation
- Designing – plan the design of the study.
- Interviewing – conduct the interview based on a guide
- Transcribing – prepare the interview material for analysis
- Analysing – decide on the purpose, the topic, the nature and methods of analysis that are appropriate
- Verifying – ascertain the validity of the interview findings.
- Reporting – communicate findings of the study based upon scientific criteria

Pages 103-104

This enables the interviewer to develop an appropriate methodology in order to obtain relevant data from the interviewees. Within this structure the researcher can develop an interview schedule to

facilitate a more effective interview process. Although not always necessary, especially when interviews are less structured and more participant-led (Smith et al, 2009), a schedule provides a means for the interviewer to prepare for the potential interview content using a set of suitable questions with an outline of potential pathways that may occur within interviews.

The development of questions for interviews is central to the interview process. How this is achieved can involve differing approaches. In the case of the more structured style of interviewing, the need for greater planning is a necessity. Weiss (1994) suggests compiling a “topics-to-learn-about” list which can then be broken down into lines of enquiry from which interview questions can then be developed. Interview schedules assist in organising the overall structure of the interview which can consist of not only the line of inquiry, but also other aspects such as opening and closing questions, as well as some of the communication and active listening skills required by the interviewer. When considering the use of appropriate opening and closing of an interview is as important as the main body of questions. The initial set of questions will often centre upon clarifying biographical information as well as providing the participant with the clear aims of the research and “housekeeping” information such as confidentiality of information provided. The use of such questioning also provides other functions in the initial minutes of the interview, including establishing the relationship and rapport between the interviewer and interviewee.

Concerning the type of questions utilised within the interview this is dependent upon the information required by the interviewer as well as the type of interview chosen. Additionally, when considering the structure of the questioning, the initial questions may be intended to be standardised across all the interviewees. However, there will potentially be a need to modify the questioning to match each individual, as different interviewees will possess different perceptions and different levels of education which will have an impact upon how they may interpret and subsequently answer each question (Shaffer & Elkins, 2005). It is important that the interviewer recognises and utilises this information and utilises topic markers to identify additional areas that arise within the interviewee’s answering to allow for flexibility in the interviewing process. Regardless of the need for such flexibility, the nature of the questions should encourage the interviewee to talk at great length whilst

the amount of verbalising by the interviewer is kept to a minimum. This will be guided by the type of questions used and their order.

In relation to the present study, the interview schedule contained a range of questions including open-ended, closed, and prompt style to ensure a wider range of response from the interviewees. The questions were based upon the main themes highlighted within the literature review discussed in Chapter Three. The final interview schedule also included a “script” for the introduction and ending of the interview to ensure both consistency in the content used and that relevant issues (e.g. confidentiality and storage of interview material) were covered with the interviewees (See Appendix C for the final interview schedule).

4.2.4 Procedure

Building upon the present researcher’s previous experience in engaging schools, this study utilised a different methodology including a different approach regarding the engagement of relevant schools. This was necessary due to the topic being one that many people, including professionals, find uncomfortable to discuss, as highlighted by some comments made within the author’s previous study, where one set of feedback reported – “they (staff team) felt uncomfortable completing the questionnaire due to the nature of the questions being asked”. In relation to the present study therefore, prior to the commencement of the research, the online questionnaire was provided to the head teacher of each identified school to further ensure that the school met the inclusion criteria. This was necessary because information sources identifying schools as being autistic spectrum condition specific are often out of date or incorrect. To this end, an email was sent as part of the initial contact with schools with a link to the questionnaire on the Qualtric website. In light of previous experiences, follow up contact was made by telephone and a letter addressed to the head teacher marked “Private and Confidential” which meant that should the initial email be “filtered” by administrative staff, the follow up letter would reach the head teacher directly.

Once contact had been made with the school and participant, the school had been confirmed as meeting the study inclusion criteria, and the school and participant had declared themselves willing to participate in the study, the next stage was implemented. This involved the use of semi-structured interviews with the school's headteacher or a designated staff member responsible for the implementation of the sex education programme.

The aim of the interviews was to obtain both factual information and themes relating to each school's policy and procedure in the implementation of the SRE programme which could be reinforced by a review of written evidence (e.g. policy documents), as well as exploring the interviewee's knowledge, understanding and attitude in relation to SRE programmes and issues relating to inappropriate sexualised behaviour. Due to the additional issues relating to pupils having autistic spectrum conditions, there were also questions relating to the specific needs of teenagers with these conditions in order to ascertain how such needs are dealt with, if at all. Subsequently, the data obtained would enable a comparison across schools in relation to how SRE programmes were implemented, which could compare both similar types of school as well as examining data for all the schools.

Structured interviews often involve specific questions requiring pre-coded responses. These responses can often be simply recorded on some form of response sheet. In the case of semi-structured interviews however, questions are more liable to be a mixture of open-ended and closed questions. Subsequently the use of response sheets becomes difficult and more advanced methods may be required. These may include voice and/or video recording along with note taking, which raises additional confidentiality issues as the interviewee will be more easily identifiable. The use of multiple data recording methods can aid in reducing the possibility of data being lost during and after the interview. In this case, the interviewer utilised a voice recorder along with note taking in order to ensure that a true reflection of the interview was available to complement the notes and minimised the risk of potentially key information being lost. Upon completion, each interview was transcribed to enable more comprehensive analysis (Feldman et al, 2004), and the recordings were stored securely using password protection to ensure confidentiality.

4.2.5 Ethical Issues

Throughout the research process the researcher was confronted by ethical implications that required consideration and handling (Kvale, 1996). This is important within social sciences as the collection of data will invariably involve people, and so it is imperative that the participants' rights and safety are safeguarded (Punch, 1994). To ensure this, a number of general ethical principles have been developed, (Punch, 1994; Thome, 1998) to guard against harm. These are:

- **Beneficence**

The principle of beneficence centres upon ensuring that research should benefit participants and wider society (Murphy, 1993). In relation to the present study, the aim was to explore what sex education programmes are available in order to ascertain how to improve the support for individuals with Autistic Spectrum Disorder. The other aspect requiring consideration in relation to beneficence centres upon post-study impact upon participants. With the increased attention that participants receive during any study, the eventual withdrawal of such attention can provide them with a feeling of isolation (Parraho 1997). This is particularly the case with vulnerable participants but less of a problem with professionals. Concerning the present study, feedback was provided in relation to results to ensure some benefit to participants.

- **Non-maleficence**

The issue of non-maleficence centres upon the researcher's obligation to do no harm to participants (Thome, 1998). The obvious aspect would be physical harm, but it is just as important to consider the psychological aspects (Parraho, 1997) that can occur. To overcome any potential harm that could occur, the present study only involved specific staff who had provided informed consent. In order to gain such consent, participants received background information sheets (See Appendix D) concerning the study at the point of recruitment. This background information was then discussed prior to the interview commencing and a consent form (See Appendix E) was completed and signed by each participant. An additional aspect to ensure no harm involves each interview transcription and recording being stored

confidentially, including privacy from their own organisations. In relation to the present study, all interviewees were given code numbers and all feedback given in relation to the results was provided anonymously, thus ensuring that participants would be able to participate without worries that their organisation would recognise comments made and potentially react negatively (Seale et al, 2007).

- **Fidelity**

When someone chooses to take part in a study, they are placing their trust in the hands of the researcher. Such trust is very much based upon the extent to which the research adheres to the original plan (Mowbray et al, 2003). As such, it is not the researcher's right to change any aspect of the study or continue the study just to achieve their targets (Parahoo, 1997). Not only does such change impact upon elements of trust, it also brings into question issues of validity in relation to the results (Horner et al, 2006). For the purpose of the present study, the basis of the interview would be an interview schedule (See Appendix C) in order to guide each interview along and increase consistency. The aims of the study were made clear in information sheets provided to participants.

- **Justice**

Justice within research is based upon the idea that the researcher should ensure impartiality, equality and reciprocity (treat others as you would want to be treated) (Beauchamp and Childress, 2001). Within the present study, the researcher's knowledge of some of the participating schools but not all had to be taken into account. Using the previously mentioned interview schedule, the consistent structure of each interview ensured impartiality and equity across the various interviews that took place.

- **Veracity**

The issue of veracity within research is part of the development of trust between participant and researcher. Veracity is based upon the presence of truthfulness in what the researcher says about the study, even if the results of such truth leads to participants declining to

participate within the study (Parahoo, 1997). The issue of truth and research veracity also contributes to the autonomy possessed by participants (Gillon, 1994). To help toward autonomy, the present study information sheets and interviews incorporated an outline of the study aims as well as future plans, including how the present study fits into the overall situation.

- **Confidentiality**

The principle of confidentiality enables the participant to take part in research without details and information being disclosed to others (Parahoo, 1997). Ensuring strict confidentiality protocols within a study, particularly for interviews, often allows participants to feel more confident to talk (Somekh & Lewin, 2006).

Concerning the present study, each participant was informed verbally and in the written materials about the methods of ensuring confidentiality. On a practical level, the questionnaire only identified the participant in connection with known but anonymised school information. Both this and the subsequent face to face interviews have been stored within a secured environment only accessible by the researcher.

- **Consent**

Consent has already been briefly discussed within these pages. There have been many discussions relating to the use of both informed consent and covert research, both of which have a place within the social research field. However, for this particular study informed consent was most relevant. In order to gain informed consent from a participant, the researcher needs to explain in advance what the overall purpose of the research is along with the main aspects of the study including all potential consequences: both negative and positive (Kvale & Brinkmann, 2009).

Informed consent within the present study was obtained in a number of ways. Firstly, the initial contact with participants included details about the study (See Appendix D) outlining

its main aims. At this point, potential participants who completed the online pre-interview questionnaire were assumed to have provided consent through the completion of the questionnaire. Following on from this, at the start of the face to face interview further discussion about the aims of the study and confidentiality occurred in order to clarify any issues that the participant may have wanted to discuss as well as confirming that they still gave consent.

Ethical approval was sought from the Tizard Centre, University of Kent's Ethics Committee, (See Appendix for a copy of the approval letter F), as there were no specific educational ethical committees to contact in relation to local authority schools, and any schools run by independent organisations often only require clarification about the research. The only additional approval that was required came from the head teacher in order for either him/her or a representative to have participated in the research. No parental consent was required as no pupils were directly involved with the research. Participants were also made aware of the Complaints Procedure in case they had any issues with the process or researcher.

4.2.6 Analysis

The data obtained from the pre-interview questionnaire was analysed using SPSS analytical software in relation to the general information and content to provide demographic details about the schools and provide comparison between participants.

In relation to the analytical process for the interviews, the choice of which method to use depends very much upon the approaches that have been taken within the research, as well as the expected outcomes. With regards to the present study, two main approaches were considered: Grounded Theory and Applied Thematic Analysis. A third option was briefly considered: Interpretative Phenomenological Analysis, which is an approach that has been developed (Smith et al, 2009) centring on exploring the lived experiences of an individual and how that individual has made sense of the experience. Although such an approach is useful when utilising interviews to obtain qualitative data, in this particular situation the data being explored primarily relates to factual processes within

the implementation of sex education programmes. Therefore, only the first two options were explored in relation to appropriateness for the present study.

Grounded Theory

Grounded theory was developed by two sociologists in 1967. They defined grounded theory as ‘the discovery of theory from data systematically obtained from social research’ (Glaser & Strauss, 2006, page 1) Although over the years grounded theory has developed with many versions appearing (Dey, 1999), the underlying principle has remained the same, ‘the discovery of theory from data’ (Glaser & Strauss, 2006 page 1) Although literature is explored, the research involved in grounded theory has no pre-conceived theory being proposed or any particular hypotheses requiring testing. Instead, grounded theory is described as starting with an open mind which avoids theoretical preconceptions, but which often originates from a point of interest for the researcher and ends in a theory (Dey, 1999). Consequently, data collection methodology within grounded theory is different to more traditional research methods, as in the former the researcher commences with some initial research questions which guide the data collection. As each phase of data collection occurs, it develops its own themes, so the research evolves until theoretical saturation (no further themes are emerging) is reached.

Applied Thematic Analysis

In contrast to grounded theory, applied thematic analysis is relatively ‘new’ since first being named in the 1970s (Merton, 1975). Since then there have been a range of different versions, but generally it is a qualitative analytic method that involves:

‘identifying, analysing and reporting patterns (themes) within data. It minimally describes your data set in (rich) detail. However, frequently it goes further than this, and interprets various aspects of the research topic.’

Braun and Clarke, 2006, p.7

Although as with grounded theory sets of themes are identified within the dataset in order to attempt to answer the specific research questions being asked, applied thematic analysis has greater theoretical flexibility than grounded theory which allows greater inductive exploration of the data (Guest et al, 2012). This results in the coding process not being rigid in trying to fit the data into pre-existing coding framework, but actually allowing the themes to develop within the analytical process. As with other analytical methods, applied thematic analysis comprises a number of steps in order to achieve the overall analysis. In relation to Applied Thematic Analysis, an outline of six phases of analysis (Braun & Clarke, 2006) includes:

1. **Familiarisation with the data:** Whether this involves verbal data via transcriptions or some other form, it is imperative that the researcher becomes familiar with the data that has been obtained.
2. **Generating initial codes:** Once the researcher is familiar with the data then the generation of initial codes from the data can occur, followed by the collating of the codes and all relevant data extracts.
3. **Searching for themes:** Searching for themes within the data occurs once the initial coding has finished.
4. **Reviewing themes:** At this stage, the researcher may discover on reviewing the data and identified themes that some parts of the data, though interesting, are not substantive enough to constitute a 'theme'. Consequently, themes can be refined so that the final themes provide a clear "story" about the data.
5. **Defining and naming themes:** Once the researcher is satisfied with the resulting themes, a more detailed analysis of each theme can occur including providing an appropriate name for each one.
6. **Writing up:** This phase can only occur once the researcher has a full set of clear themes which are then analysed within the write up of the results.

In relation to the present study, the decision was made to use the applied thematic analysis to analyse the data obtained from head teacher or school representative interviews due to its greater flexibility. This was particularly important within this study as, although there was an underlying theory about

the issue of sex education programmes, increased flexibility enabled the researcher to explore a range of issues relevant to the situation which were not necessarily initially considered. Also, the use of applied thematic analysis has been seen as more appropriate and commonly used in the public health research (Green et al, 2007) due to the nature of the process.

In addition to the analytical methodology being chosen, the use of data triangulation needs to be considered in order to potentially reduce the uncertainty of the data interpretation (Webb et al, 1966). By comparing two sets of data, in the case of the present study the results of two separate researchers reviewing a number of transcriptions (Guest et al, 2012), it provides some indication as to the reliability of the analysis. This is especially true when the reproducibility across coders are 80% or above. However, although there has been much written about the processes and targets for intercoder reliability, as highlighted by Campbell et al (2013) there has been little exploration into the process when used with in-depth semi-structured interviews. Such a lack of exploration also involves a distinct lack of discussion surrounding the use of such processes within published studies involving semi-structured interviews (Lombard et al, 2002). There are indications that this lack of discussion and usage of intercoder practices is linked with the nature of the resulting data (e.g. words and statements) being more open to misinterpretation as well as issues surrounding the context (Miles and Huberman, 1984). Additionally, some researchers feel that the non-standardised nature of the resulting data means that, in comparison to numerical data or the results of structured interviews, any measures or test used for reliability would be less reliable (Armstrong et al, 1997; Miles and Huberman, 1984)

Regardless of the various views concerning the reliability of intercoder analysis results, there have been attempts to develop guidance with regard to the methodology behind the process (Campbell et al, 2013). This highlighted some of the difficulties involved with the process, such as whether secondary coders/researchers should only analyse sections of data which could cause contextual difficulties, as well as issues relating to ensuring that the coding system used was kept simple. Where differences have occurred within the analysis of semi-structured interview data, some researchers have proposed the use of “negotiated agreement” (Garrison et al, 2006). This involves coders

discussing any disagreements they may have in their results, but this can be affected by the knowledge levels of each coder as well as their ability to effectively negotiate with each other.

With regard to the present study, the combination of issues raised concerning the processes and the time constraints placed upon the present study meant that the use of a second coder proved difficult. Due to the nature of the participants being school based, there was an automatic time limit for the study to occur, namely rigid term times. Additionally, the amount of data that required analysis was considerable, requiring much time to be assigned by those analysing it in addition to any training, etc. With such rigid time scales as enforced by the nature of the participants meant that the ability to find and potentially train an appropriate second coder proved difficult to achieve. This was both within the time scale and also difficulties for many potential coders to commit to because of other research or work commitments. Consequently, the decision was taken by the lead researcher to proceed with the analytical process without a second coder, as well as performing the analysis in a more inductive manner without any predefined coding scheme. Such an approach is not unheard of as Campbell et al (2013) discovered when they questioned a number of researchers with regards to the methodology utilised. Although some did utilise a more formal coding and second coder approach, there were some that followed a similar pathway to the present study. When looking at the situation with those researchers that followed a more structured approach to their analysis issues still arose, particularly regarding unitisation (Krippendorff, 1995) which occurs when sections of text are provided out of context, requiring the coder to make a subjective interpretation. This can result in differences in each interpretation dependent upon how much text has been made available and the perspective of each coder, particularly when utilising more open-ended questions as was the case of the present study. Consequently, as there does not necessarily seem to be a perfect method for the analysis of semi-structured interviews, the fact that an entirely inductive approach without any predefined coding scheme was used within the present research should not necessarily reduce the strength or reliability of the present study.

Following completion of the analysis and write up of the results, the researcher disseminated the information to all interviewees via an anonymised summary report. conferences presentations and subsequent publications will follow.

4.3 RESULTS

4.3.1 Participant school characteristics and results of on-line survey

Demographics

In total 17 individuals from the final 15 schools participated in the interviews. In the case of two schools, two individuals were interviewed as they shared the role of SRE co-ordinator. The overall breakdown of the interview participants included 11.76% (n=2) were male, 88.24% (n=15) were female. In relation to each participant's position in the school, 41.18% (n=7) were teachers who were the designated SRE co-ordinator, 11.76% (n=2) were speech and language therapists assigned to develop an SRE programme, 23.53% (n=4) were deputy/assistant headteachers and the same amount (23.53% (n=4)) were headteachers.

Study sites were recruited from three areas in the south east of England; North & South London, Surrey and Sussex. Identification of potential participants was achieved via various databases, including the National Autistic Society school list and relevant local authority sources. Once identified, potential participants were contacted and relevant information provided to enable them to make an informed decision about participating in the study. Following agreement being obtained from the study sites and specific individuals, each site was asked to complete the online pre-interview questionnaire which provided some background information regarding the school (See Appendix B). As a result of this process, 16 sites were recruited for the study, although one was discounted later in the process due to being unable to commit to providing an appropriate contact person for the study.

School Details

Geographically, of the 15 sites 20% (n=3) originated from Sussex, 20% (n=3) originated from Surrey and 60% (n=9) from London. However, not all schools were able to provide demographic data due to a number of technical issues with the online questionnaire and changes in personnel. This led to 4 sites being unable to complete the whole of the pre-interview questionnaire.

Although the aim was to recruit schools from a range of differing types, only two categories of school were eventually involved in the study as these were the only types to respond. The school types finally involved were from either Autism specific provision or from learning disabilities provision (where a diagnosis of autistic spectrum condition is very common). The breakdown of the schools was 20% (n=3) autism specific provision and 80% (n=12) were classed as primarily providing for individuals with a range of learning disabilities. Concerning the composition of the larger group, two were classed as specialising in Social, Emotional and Mental Health issues, one specialised in Speech, Language and Communication issues, and the remaining were for pupils with varying degrees of learning disabilities.

No mainstream schools took part although some were contacted as they had a specialist autism unit attached. Unfortunately, the schools either declined to take part or did not respond. Consequently, the pupil populations accessed were small compared to mainstream schools. The total number of pupils within the schools ranged from 64 to 220 with an average amount of students being 132.7 of the 11 schools providing data. The gender distribution showed that there were more boys than girls attending the schools, which is expected considering that generally more boys than girls are diagnosed with autistic spectrum condition. One school did have more girls than boys, but this particular school accommodated a wide range of additional needs compared to other schools. Age ranges were split into 4 groups (0-4; 5-11; 12-16; 17+) (See Fig 4.3 for group totals). Of the 11 schools, only 3 covered all four age ranges as they provided support from nursery age up to post 16 facilities. Of the remaining 8, one school provided nursery and primary facilities, three provided for primary and secondary ages (5 yrs – 16 yrs) and four provided for secondary and post 16 (11yrs – 19 yrs).

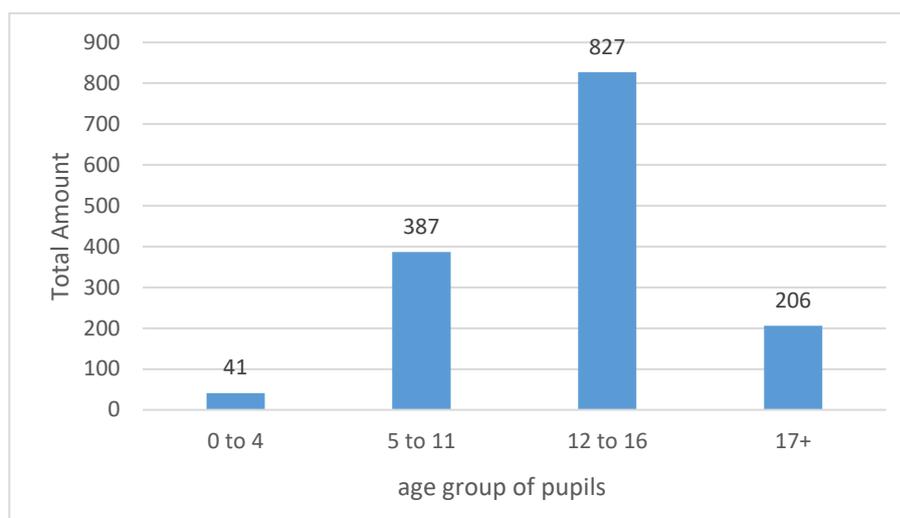


Fig. 4.2 – Total Numbers of pupils in each age group across all schools

Regarding ethnicity, the distribution amongst the schools were predominantly white with seven schools reporting 51% or above of the school population being within this group. Regarding the other groups, the Asian group were the only other one to have 51% or above but this was in one school whilst other schools reported numbers to be generally less than 30%, mixed race groups were generally less than 30% across the schools, and the Black grouping was less than 40% with most schools reporting less than 30%. (See Table 4.1 - for results).

		Ethnicity				
		White	Mixed Race	Asian	Black	Other
Schools	1	F	A	A	A	A
	2	B	A	F	B	A
	3	F	B	B	D	A
	4	F	A	A	A	A
	5	F	A	A	B	A
	6	F	A	A	A	A
	7	B	C	C	C	A
	8	F	A	B	A	A
	9	C	B	B	C	A
	10	B	A	A	C	A
	11	F	C	B	B	A

Key

A = Less than 10%

B = 11-20%

C = 21-30%

D = 31-40%

E = 41-50%

F = 51% and above

Table. 4.1 - Ethnic distribution for each participating school

The ethnic demographics of the schools depended on their location: those (8) in outer London/Surrey/Sussex being less ethnically diverse. The remaining four reported higher percentages of minority groups, as reflected in their geographical location (Inner London).

When examining the distribution of diagnoses within the school, in addition to autistic spectrum condition/Asperger’s Syndrome participants were asked to identify other conditions:

- ADHD
- Dyspraxia
- Downs Syndrome
- Cerebral Palsy
- Oppositional Defiant Disorder
- Obsessive Compulsive Disorder
- Dyslexia
- Other (to be specific by participants)

Diagnosis

School	Asperger’s Syndrome	ASD	ADHD	Dyspraxia	Downs Syndrome	Cerebral Palsy	ODD	OCD	Dyslexia	Other
1	D	A	A	A	A	A	A	A	A	F
2	B	F	A	A	A	A	A	A	A	A
3	B	F	A	A	A	A	A	A	A	A
4	B	C	A	A	A	A	A	A	A	F
5	B	C	A	A	A	A	A	A	A	A
6	E	F	B	A	A	A	B	B	A	A
7	A	D	A	A	B	A	A	A	B	A
8	A	C	C	1	A	A	A	A	A	D
9	A	F	A	A	B	A	A	A	A	A
10	A	F	A	A	A	B	A	A	A	A
11	D	E	D	C	A	A	B	B	A	A

Key
A = Less than 10%
B = 11-20%
C = 21-30%
D = 31-40%
E = 41-50%
F = 51% and above

Table 4.2 - Distribution of Diagnoses within each school

As expected, and as indicated in Table 4.2, due to the inclusion criteria, the main diagnoses identified as being more prevalent were autistic spectrum conditions and Asperger’s Syndrome. Asperger’s Syndrome was separated from autistic spectrum condition as many of the schools had pupils diagnosed with this prior to the changes in diagnostic terminology. With regard to the remaining conditions, ADHD was identified by three schools as being present within 11-40% of the school population. The remaining diagnostic categories were generally identified as being less than 10% with 1 or 2 schools stating 11-20%. These latter schools provided support for a range of special needs.

In comparison to the other requested information, the reporting of behaviours was open to interpretation and knowledge of those completing the survey, as well as the level of recording regarding incidents of behaviours. Consequently, much of the data acquired was an estimation by the individual completing the questionnaire (See Table. 4.3 for results).

Exhibited Behaviour

	Physical Abuse	Verbal Abuse	Self-Injurious Behaviour	Damage to Property	Refusal to participate	Sexual Behaviour	Other
1	F	F	B	E	D	B	A
2	D	A	B	A	B	A	A
3	A	A	A	A	A	A	A
4	A	A	A	A	A	A	A
5	A	A	A	A	A	A	A
6	B	B	A	A	A	A	A
7	A	B	A	A	B	B	A
8	E	D	A	C	E	A	A
9	B	B	A	A	B	A	A
10	B	B	A	B	C	A	A
11	C	C	A	C	C	A	A

Key

A = Less than 10%

B = 11-20%

C = 21-30%

D = 31-40%

E = 41-50%

F = 51% and above

Table 4.3 – Distribution of Behaviour Type within each school

The resulting data indicated that there were occurrences of each of the six behaviours, the main areas of difficulty being physical abuse of others, verbal abuse of others, damage to property and refusal to participate. All four were indicated to be up to 41-50% except physical abuse of others and verbal abuse of others both of which were in one case over 51%. The remaining 2 types of behaviours were

recorded as being low occurrence with only two participants reporting a maximum of 11-20% occurrence.

The final set of information acquired centred upon the general support services available to pupils, parents/carers and teaching staff. Across the results (See Fig 4.4 for results), there were a number of common services highlighted, such as school based counsellors, access to an Educational Psychologist, use of various therapies (e.g. Speech and Language, Occupational, Drama therapy, Art Therapy), and access to local Child and Adolescent Mental Health Services (CAMHS). Some services mentioned by schools were in-house, others were external.

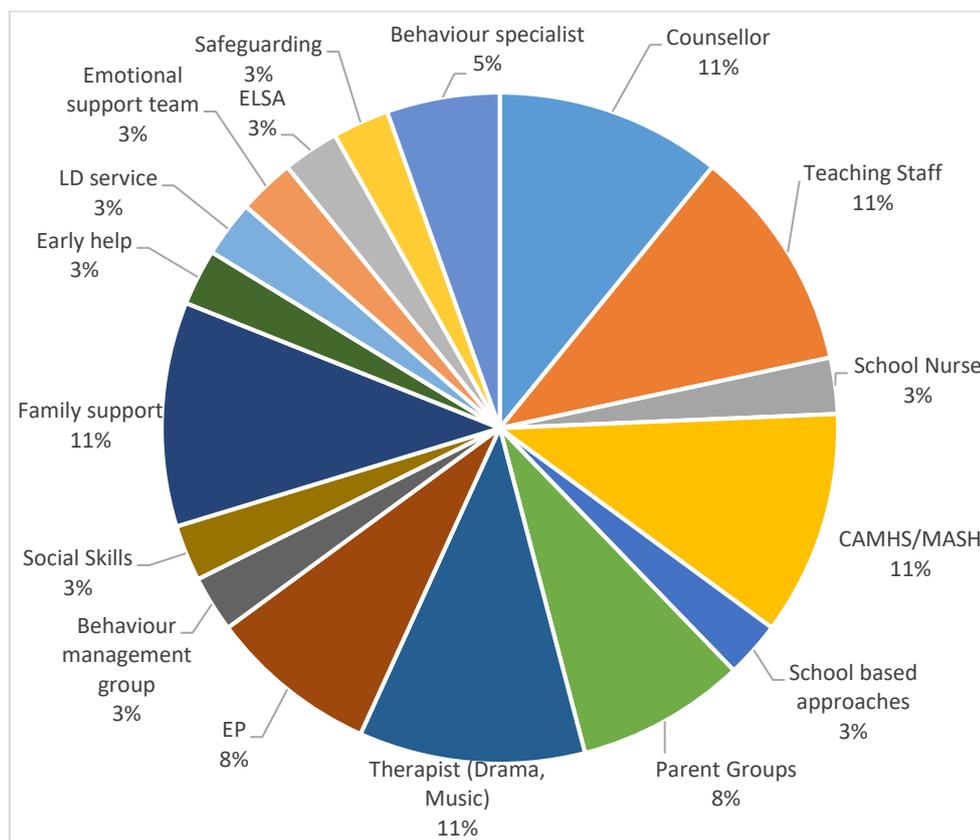


Fig. 4.3 - Support Services Accessed by schools to support pupils' behaviours

In addition to these generic services, there was a range of support approaches that were either specific to the school or were an alternative to other services. These included:

- Parent Groups. This involved specific training for parents and also support groups for parents to regularly meet with others to talk about their experiences.
- Pupil specific behaviour/emotion groups to support pupils in dealing with issues.
- Family support workers/Resilience workers to help with issues at home.
- Emotional Literacy Support Assistant (ELSA) to work with pupils in understanding and dealing with their emotions.
- Behaviour Specialist
- Teaching staff were identified in 11% of cases, although teaching staff would have been involved with all pupils, but this seems more related to staff that were specifically trained in behavioural support and intervention.

Overall, although the data obtained from the survey did not explore in any in-depth way the topic of sex education, it did provide some background information in order to gain some understanding about the aim and practices of the schools accessed.

4.3.2 Interview Results

The analysis of the interview data involved a three-stage process (Creswell, 2007); data preparation for analysis (achieved via transcribing), thematic analysis of the data, and presentation of the data. Initially, each interview was transcribed and the transcriptions were read repeatedly alongside the audio recordings to ensure that they were representative of the interviews and that the central questions posed as part of the interviews had been answered. This was then followed by a more detailed analysis focussed upon identifying initial overarching themes (Guest et al, 2012). Further review of the data identified a number of sub themes comprised of specific issues raised within the transcripts (Hesse-Biber and Leavy, 2011). All the overarching themes and subthemes were reviewed on a number of occasions and resulted in Figure 4.4 which outlines these themes.

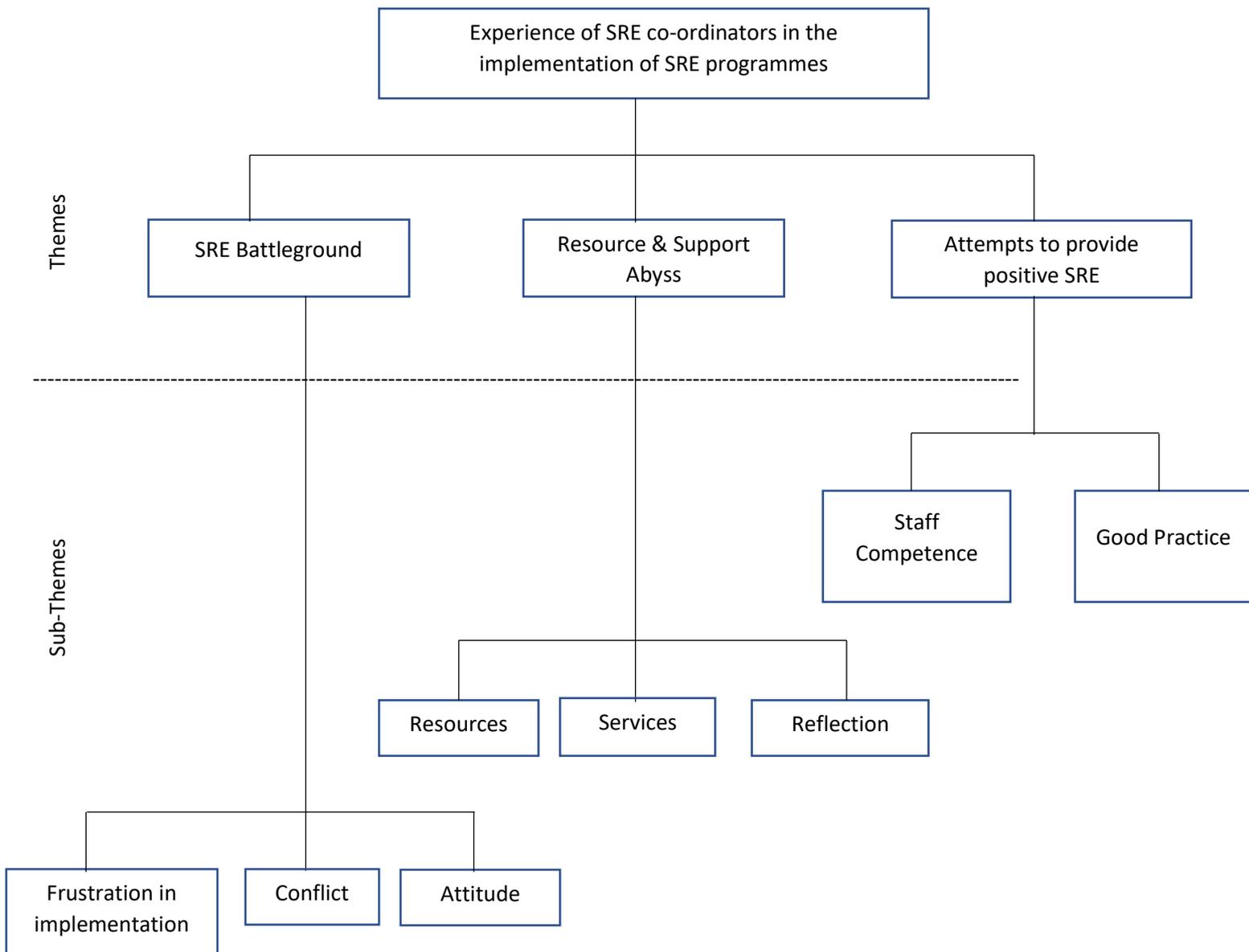


Fig. 4.4 – Interview Themes

4.3.2.1 Over Arching Theme - SRE Battleground

Throughout the interviews, regardless of whether good practice was present or not, an overarching theme became apparent regarding the conflict between the co-ordinators and the various establishments, (e.g. senior management and Ofsted), linked with the schools. Such establishments were not necessarily purely educational, but also included difficulties regarding societal, moral and cultural views of those within the establishment regarding openly discussing the topic of sexuality and relationships generally, as well as regarding people with Autistic Spectrum Condition. The impact of such conflict resulted in difficulties in effectively implementing SRE programmes for affected

individuals, and so reduced the chance for a firmer knowledge-based foundation to be established with the individual. Being constantly faced with such battles in developing and implementing such programmes led to several of those interviewed expressing how frustrated they had become, but that they continued to battle on for the sake of the pupils as they recognised the importance of SRE.

“Other things come far higher up the list because they’re things that Ofsted inspectors look at all the data. They don’t want to see the data for how children are progressing with their sexual knowledge.”

Deputy Head Teacher, School C

Sub theme - Conflict

Central to the overarching theme of being in an SRE Battleground was the feeling of some SRE co-ordinators as conflicting with others. This was never felt more so than when dealing with the tensions of societal views and attitudes of those around them. Primarily, this attitudinal difficulty originated from other school staff, especially senior management and teachers. The data acquired within the interviews highlighted several difficulties relating to the consistent implementation of the programmes. In several interviews, participants discussed difficulties relating to certain staff’s reluctance to teach the necessary subject. This reluctance to participate in the delivery of the PSHE programme was seen by some participants as being linked to several issues. Some of these originated from a belief system whilst others were more personal to individual staff. Regarding the latter, many of the concerns had links to lack of skill and knowledge possessed by the wider teaching staff. This often resulted in the wider teaching staff feeling unskilled regarding teaching the subject correctly due to a lack of effective guidance and training commitment from senior management. Often teaching staff expressed their concern to the co-ordinator that they were not teaching either the correct information or in an appropriate fashion, and so were reliant upon the co-ordinator to guide them. However, this would prove difficult in those circumstances where the co-ordinator role was not well resourced or supported by senior management.

As well as the actual teaching process, there were difficulties highlighted in relation to teaching staff's views upon whether pupils should be taught such a subject. Often such decisions were based upon the perceived needs and ability levels of the individual with autistic spectrum condition from the perspective of staff. Alternatively, the difficulty regarding information taught could have been due to staff's own attitudes about sex education.

"It depends on the teachers you have got, some are very empowered by it (SRE) so it has to be done, others will cower away even when it says on your planner that you've got to do it"

Headteacher, School L

Unfortunately, as the participants highlighted, the view that pupils with autistic spectrum condition should not be taught anything about SRE was still held by professionals regardless of the evidence against such issues. As also highlighted within previous studies (Katoda, 1993; Ryan & McConkey, 2000; Parchomiuk, 2012; Graff et al, 2018), the issue of SRE can clash with both cultural and religious views. In relation to the interviews, such conflict was found to impact upon the implementation of the SRE programmes from both the viewpoint of staff and parents. Primarily, the difficulties associated with religious and cultural beliefs were particularly relevant to schools based in the London areas where often there was a more diverse mix of staff, pupils and parents. When examining the data obtained from the participants, the clashes regarding cultural and religious views were often more prominent and problematic within the staff team. Only one participant identified how the religious views of parents had limited one child from being involved with aspects of the SRE programme, (particularly contraception), but still allowed them access to other areas. In contrast, the cultural and religious views of the teaching staff directly involved with SRE implementation were reported by the interviewees as having a direct impact upon the overall quality of the SRE teaching, particularly the depth of the information being provided to the pupils.

“Every class teacher delivers it to their group, pretty much um, and so there, there, there lies in a bit of a difficulty which is what we’re not policing it....so we just go, we, so here’s the topic, maybe FGM ok, and I’m (teacher) comfortable with this bit of it and I’m not so comfortable with this.”

Head Teacher, School H

These issues were more prolific when the SRE/PSHE co-ordinator was not directly involved with the teaching of the programme, and such views conflicted with the appropriate implementation of the PSHE programme. Consequently, this placed more pressure upon the PSHE co-ordinator as they would have to either do the teaching or arrange for an appropriate person to do so. However, this caused additional difficulties for co-ordinators as they were unable to ensure consistency and appropriateness in the information being provided by the parents, although at least the parental view on the need for such education from some source was positive.

In some cases, the interviewee discussed difficulties connected to the school timetable. Often the topic of PSHE would clash with other subjects on the timetable. This was especially true when special events were organised, such as getting outside speakers to talk with individual classes. In these situations, often staff would highlight how their subject (e.g. Maths and English) were far more important than PSHE.

“It’s either coming in and um just saying right ok can you, (release students) and then taking them off the timetable, which never is never kind of doesn’t always go down well with other teachers, especially in core subjects.”

PSHE lead, School A

In contrast, in schools where a member of the senior management team provided input into the PSHE programme, either by directly co-ordinating the programme or supervising the co-ordinator, the issues of staff development and resources were more positive with the senior management team

often actively encouraging the development of the person in recognition of the importance of providing adequate PSHE to the pupils.

“Senior management, you know, the deputy head is really supportive in the SRE... since day one since we started writing the curriculum, she’s been involved in dipping in, and the head teacher’s also.. he’s very interested in getting everything implemented.”

Co-ordinator, School B

Sub theme – Attitude

In contrast to both the attitudinal conflict with other professionals and to previous studies, the perceived differences between parental attitude and school attitude, as discussed by the interviewees, was more positive. As highlighted by studies, (Katoda, 1993; McCabe, 1999; Stokes & Kaur, 2005; Pownall et al, 2012) the impact of parental attitude in relation to the implementation of PSHE programmes with pupils who have Autistic Spectrum Condition can have a dramatic impact upon whether an individual is in receipt of such information. However, in contrast to the staff attitude in several studies, the participants’ perceptions and experiences of parental attitude toward the pupils receiving SRE teaching was that it was mostly positive with many parents actively wanting the teaching to occur.

Due to the age range of the pupils and the nature of PSHE, there is often a requirement for the school to obtain consent from parents for their child to participate in the programme. This happens regardless of whether the school is mainstream, special needs or autism specific. However, participants reported that gaining such consent did not always prove easy to achieve. Although most participants discussed the process in obtaining consent directly from the parents via a signed consent form, several participants discussed how the process of gaining parental consent was based upon an assumption that parents should opt out rather than permission being sought for their child to participate in such programmes. This approach to consent, in some situations, seemed to be based

upon either advice from various organisations who had gone through similar difficulties in effectively obtaining parental consent, or through several practicality issues in obtaining such consent. The latter was often based upon previous experience within the school, especially those that were residential schools, as parents often did not come to school on a regular basis due to their child being transported to school by local authority transport. This resulted in general communication methods between school and parents being limited to letters or occasional phone calls which did not always result in a response from parents.

“A letter went out telling them (Parents) what we taught and uh they had to decide you know, send a like their consent, which end up being the nature of our parents is that we didn’t get consent so we’re having to chase up. So I didn’t, I changed that to an opt out letter, so unless we hear from you then, um, we’ll give, we’ll um, they they’ll (students) get sex and relationship education.”

PSHE Co-ordinator, School A

Additionally, in certain cases, further support was given to the parents during parents evening or additional sessions to clarify information and answer any questions although it is uncertain as to whether such approaches provided adequate information for parents.

“We also employed you to run a parent workshop, erm, we’ve also used, erm, in house staff to run similar type workshops before.”

Deputy Head Teacher, School D

It was reported by most participants that they could not recall any pupil being excluded altogether from participating in SRE/PSHE by parents. On occasions that such withdrawal occurred the families had felt that it was their responsibility to provide the information to the child, which meant it was

difficult for the PSHE co-ordinator to ascertain the accuracy of what was being taught within the home environment.

“And that (parent withdrawal) does happen quite regularly because of religious reasons. They say we’re going to do it with them at home. There’s some parents see it as not the job of the school and it’s the job of the family. So no no.”

Deputy Head Teacher, School C

However, a small number identified occasions when pupils had been withdrawn from parts of the programme for either cultural or religious reasons.

“The last, do you know, what it is 10 years, I looked, since the last time someone (parent) withdraw and that was a Jehovah’s Witness family.”

Safeguarding & Prevention Officer, School F

An examination of the reported withdrawals indicates that this generally occurred within schools where there was a high multicultural population, although the specific details relating to ethnicity of the families where a pupil was withdrawn was not known by the interviewee.

The impact of staff attitude, on the other hand, was apparent in the decision-making process performed by staff in relation to the perceived level of each pupil’s intellectual disability and whether it was appropriate for the pupils to receive a full or partial PSHE programme. One participant (a deputy head teacher) identified that within their school those pupils deemed as having more severe intellectual disability than other pupils as well as possessing limited communication skills, did not receive any form of SRE/PSHE. However, this decision had been made by the PSHE co-ordinator who was due to leave their post and had had their ability in the role as PSHE co-ordinator questioned in

relation to their understanding about the needs of the pupils as well as the PSHE co-ordinator's general knowledge and skill around the subject.

"It all depends on the individuals and it depends on the circumstance because if we're teaching in a group it might not be appropriate for that young person to be in that group because of what they're like and how... their understanding usually and their impact on the group."

Assistant Head, School G

In relation to pupil attitude toward PSHE, the participants provided a positive perspective in relation to pupils with Autistic Spectrum Disorder. For example, participants described the frequent enthusiasm of pupils in relation to SRE/PSHE

"They're always really excited so I can, for example, I was coming down the stairs last term and a year 10 class charged passed me to science "we're going to science cos we're doing sex ed" and it was lesson one so they were really excited."

Deputy Head teacher, School C

There were occasions however when participants identified issues relating to pupil having a poor attitude toward PSHE. The withdrawal of the pupils from the lesson was based upon the perception of staff as to whether the particular student could access the curriculum or if there had been issues relating to historical abuse. There were occasions when the embarrassment levels experienced by pupils highlighted by interviewees proved to be a barrier to the pupil benefitting from the lesson and thus remaining in the PSHE lesson. On these occasions, the situation was dealt with via additional one to one specialised sessions, often led by the class teacher or additional professionals, such as

speech and language therapist or outside agencies, depending upon the reasoning behind the need for such support.

Sub theme – Frustration in implementation

Frustration can originate from a myriad of places and the interview results reflected this. In fact, being frustrated was often seen as being a natural part of the SRE co-ordinator role regardless of the fact that implementation of SRE programmes within schools was part of governmental legislation. Of course, much frustration grew from the ongoing conflicts that occurred and hindered how the co-ordinators effectively implemented the SRE programmes. However, in addition to this ongoing conflict, often participants highlighted frustration that went beyond the boundaries of the school and organisational conflicts.

The lack of clarity within the legislation regarding the format and structure of such programmes often meant that prioritisation of SRE programmes by schools did not necessarily match that of the needs of the pupils. At the centre of this process was the development of the SRE programme via the allocation of a co-ordinator. The expectation that the co-ordinator could provide some form of comprehensive programme which aids rather than hinders pupil development within limited timescales and commitment frequently was central to an overall expression of frustration and annoyance by interviewees. Fortunately, in the majority of cases, the PSHE role was filled by a staff member who had an interest in the topic of PSHE regardless of experience and training. The latter aspect was a common complaint from interviewees.

“Well it’s not actually much training at all. I think we’ve had a couple of sessions when people have been, when we’ve had inset days.”

Assistant Head Teacher School G

In some cases, this co-ordinating staff member was part of the senior management team, (often the deputy/assistant head teacher), but mostly the individual was a class/subject teacher. Unfortunately, regardless of the enthusiasm of the individual, once in the role it was often expected that their normal teaching roles continued. This led to some participants feeling as though their SRE co-ordinator role and the development of SRE programmes was more about the school meeting the legislative tick boxes rather than any formal commitment by the senior management of the school to provide an effective SRE programme. This feeling of isolation was further exacerbated by budgetary limitations regarding training and resources that were allocated for SRE, often leading to the co-ordinator having to decide what is a priority within the SRE programme, ensuring that appropriate training is available for the co-ordinator and the staff to enable effective teaching, or that relevant resources are available for use with the pupils.

Regardless of the level of support received and the position of the co-ordinator within the school, without an effective programme structure learning cannot effectively occur. During the interviews, issues were discussed in relation to the programme structure (see next theme on Resources). However, when discussing how SRE programmes were implemented there were differences and difficulties voiced by participants. On the positive side, where the commitment from senior management was greatest, so the structure in relation to ensuring regular SRE lessons was in place. In contrast, the participants whose managerial commitment was seen as minimal demonstrated frustration in the ad hoc nature by which SRE was timetabled and implemented. Issues arose such as feeling that SRE had been “shoehorned” into the timetable or would be frequently cancelled to allow “more important” subjects (in most cases this was every other subject).

Although many participants discussed the frustration of attempting to implement an effective SRE programme with minimal managerial support, in all cases where a member of the senior management team was interviewed, further frustration arose from beyond the boundaries of the school regarding statutory bodies, specifically Ofsted. As discussed in Chapter 3, government legislation states that the expectation is that every school is expected to provide some form of sex education programme. However, the evidence regarding commitment surrounding SRE from

management and monitoring authorities, particularly Ofsted, was not obvious. In fact, although some participants felt that the social needs of their pupils were more of a priority than many other subjects, they became frustrated when confronted with the monitoring priorities laid out by Ofsted which, regardless of the pupil abilities, concentrated upon the more scholastic abilities of pupils via core subjects such as English and Maths, putting aside the issue of Keeping Safe for the pupils. In these instances, and particularly when such inspection visits occurred, often SRE was seemingly “downgraded” by the senior management team in favour of those topics that are more stringently monitored by Ofsted, e.g. English and Mathematics. Even when a senior management member was actively involved in implementing the programme, frustration remained high regarding Ofsted as the impact of such prioritisation of other topics meant that SRE programme moved down the school “To Do List” to ensure that focus upon Ofsted’s own priorities.

Although we hold it (PSHE) as a priority in our school, it’s not as much a priority as teaching English and Maths, because Ofsted say that’s the priority....They don’t come in here and look to see how sexually safe my students are, they come in here to look to see if they can count to 10....So there you go, and you know I have to play, I have to play the bloody game”

Head teacher, School H

Unfortunately, as the above quote illustrates, regardless of the views and knowledge of staff, the oversight of Ofsted as an organisation influences the recognition of the additional needs of pupils with Autistic Spectrum Condition beyond the academic. Such difficulties increase the never-ending frustration experienced by schools as they attempt to accommodate the conflicting needs of legislation and long term social needs of their pupils. In some cases, this had a long-term impact upon how the programme developed as time was limited to focus sufficiently upon the topic. Such difficulties were frequently discussed by participants who had become increasingly frustrated in their fight for the importance of the subject with senior management and Ofsted due to the lack of perceived insight into the actual priorities in the needs of the pupils. This was especially true when the participant originated from a school that provided support for pupils with autistic spectrum condition who had more severe difficulties.

4.3.2.2 Over Arching Theme – Resource and Support Abyss

Regarding the implementation of SRE programmes, often participants highlighted how the mechanical, biological aspect of SRE, including sexual intercourse, are the easy concepts to teach due to the apparent “black and white” nature of the topic. Frequently this section of SRE was either incorporated into the generic school biology lesson or was covered in both Biology and SRE.

Sub Theme - Resources

Regardless of how the subject was taught, once again the SRE co-ordinator was faced with further issues regarding ensuring that the teaching was done consistently and appropriately whilst also linking in with the wider topics that were involved with SRE. These topics often involved the more abstract socio-sexual aspects of everyday life which proved more difficult to teach. Such difficulties were frequently reported within the interviews as occurring due to the fluid nature of social rules and interactions that occur in everyday life and that have an impact upon how friendships and more intimate relationships grow and develop. In an attempt to overcome these issues, a limited number of interviews (n=4) highlighted how the participant had researched some of the SRE programmes for individuals with intellectual disabilities that had previously been developed and published. They had subsequently attempted to utilise such programmes within their own schools, but this often proved difficult to effectively implement due to the wide range of abilities and needs of the pupils involved. For most participants, the search for appropriate teaching materials for pupils with autistic spectrum condition in the absence of any appropriate formally structured programme led to considerable amount of time being taken up in attempting to develop what was required, thus increasing the frustration experienced by co-ordinators who were generally committed to providing a comprehensive programme.

The need to adapt approaches within the general school environment was recognised as a necessity for individuals with Autistic Spectrum Disorder. Within those schools that provided specifically for this group of students, or for those with intellectual disabilities, such adaptation was part of the overall approach. In these schools, staff had been trained generally in a range of approaches that

were appropriate for individuals with Autistic Spectrum Disorder, as well as those with intellectual disabilities, such as TEACCH, Picture Exchange Communication System (PECS) and appropriate levels of structure.

“There is lots of differentiation going on but in the classes where it’s predominantly Autistic Spectrum Disorder we’ve become, we’re becoming a communication friendly school.” Deputy,
School C

“It varies so everything from the very basic things like individual timetables, everything visualised down to very very specific assessments.”

Safeguarding & Prevention Officer, School F

Regarding materials for the SRE programmes, aside from the frustration experienced by co-ordinators in obtaining appropriately adapted material, some interviewees felt that what was available was lacking the necessary rights based approaches that was required for the situation. As previously highlighted, many participants felt that the emphasis of much of the material centred upon the mechanical side of SRE. Where further elaboration in the material occurred, this only centred very much upon safety and legal issues. Many participants felt that to effectively support the pupils, there was a need to utilise an approach that could expand upon this, looking further into the socio-sexual aspects and how it relates to the individual’s rights and needs. Although certain aspects, such as relationships, were often taught separately to the SRE programme, the way in which such approaches were utilised led to pupils having difficulties in making the various connections between the different lessons and teaching methods. In practice, this often involved pupils attending separate social skills/relationship classes, some time away from the SRE programme instead of as an integrated programme. This separation was felt to cause pupils difficulty in regard to connecting everything together in a logical fashion, and that could then reduce the potential for pupils to generalise their knowledge and skills further.

An aspect of the approaches used within SRE programmes that was often raised by participants in regard to programme implementation related to the difficulties faced by co-ordinators in providing appropriately individualised methods which took into account the varying levels of understanding amongst the pupils as well as being more autism specific in its methodology. Both aspects were felt to be imperative in regard to the pupils with a diagnosis of autistic spectrum disorder considering the varying additional issues that can occur due to their diagnosis.

“They’d access the same content of the curriculum and they’re not taught separately... they are involved because we believe that the picking of the skills of socialisation and relationships and interactions is fundamental for their development.”

Head Teacher, School E

In some situations, attempts were made to cope with the variance in abilities amongst the pupils by utilising graded levels of targets for the teaching depending upon the assessed ability levels of individual pupils.

“In the post 16 we have like an assessment checklist of all kinds of life skills and it covers relationships as a part and sex ed as another part.”

PSHE co-ordinator, School O

In one case this centred upon a three-tiered measure of each pupil’s knowledge acquisition as set by staff, although this did not necessarily measure the pupil’s ability beyond the “black and white” knowledge level. In other situations, this grading was done more in regard to the specifics of the class abilities and would often involve individual classes being divided into subgroups (8-12 pupils) based upon pupil abilities as perceived by staff, often with at least one group being more autism specific;

“We work in about groups of 8-10 and then those children would be broken down into, maybe, groups of 3”

Head Teacher, School H

“We have, um, currently three what we call high needs classes and those are for students who really don’t cope well with the ah, the sort of busy toing and froing of a of a other classes and they work in a very structured way.”

PSHE co-ordinator, School N

“When it’s time for PSHE they’re split into slightly different groupings. So they’ve moved from their class groups where their multi mixed ability to a more, a more able discussion group. Another group sort of limited verbal communication and who.. need a lot of support.”

PSHE Co-ordinator, School N

This methodology was not necessarily based upon any formalised decision-making process, but more to the staffs’ judgement in regard to the needs and abilities of each pupil. In those situations, where pupils were deemed as not having the capacity to consent, the subject of sexual interaction would be limited to what they were not ‘allowed’ to do. In many cases, these smaller groups would require differing levels of teaching including the content of what was discussed. For example, one school had split a class of 12 into three groups with those deemed as less able and not possessing the capacity to consent to a sexual act being taught basic information about body parts, whilst the abler students were being taught about sexual relationships.

“We’ll support them individually I mean we had some students this year erm we had we had some students that were I would say too low ability to access it, so you know we we tend to do what things when students are too low ability to have understanding of it, we do about keeping safe erm

lower impact kind of programme with about keeping safe within the class with the teacher and the support staff.”

Assistant Head, School G

In contrast, one particular school discussed how they frequently have to adapt the programme to accommodate students that seemed to possess some limited social skills but which were still not at an appropriate level for them to be safe, however they were spending a lot of time with more able, neuro-typical people outside of the school environment. This had placed them in difficult positions due to issues in understanding some of the coercive techniques being used by others.

“If there are a couple of students that were perhaps at a different place because socially even though you might have them all here socially they can be very different. I might have young people out with their mates at night and another that has never left the house, because mum, because they couldn't be. So for those we might do something slightly different. They might, we might, then with those people we might be doing about how to keep safe when your outside the house, you know, have you got your phone on you, have you got your keys, um and for a very few in year 9 we might be doing contraception um who can you go to for advice, etc.”

PSHE co-ordinator, School G

The impact of having to provide differing levels of teaching was reported by the co-ordinators as being problematic due to the need to adapt programmes further for those with Autistic Spectrum Condition, especially when many commented upon the lack of autism specific SRE/PSHE programmes.

“When you said what could be improved I bet there could be a fantastic visual pack erm that could be created erm that would really be beneficial to er autistic kids in particular over on the step side erm so something like that because at the moment teachers have to make their own resources or find their resources that erm but if there was a real you know autism friendly erm pack with various different

levels differentiating would be fantastic and then those kids that couldn't manage and needed that individual input actually support workers could work with them but most of them would probably go ew you know I'll leave it to the teacher"

Headteacher, School L

However, the process of developing and obtaining appropriate materials for pupils with Autistic Spectrum Condition often took up a huge proportion of the co-ordinator's time which proved difficult when the interviewee also had ongoing teaching commitments. Even when specific programmes developed for individuals with intellectual disabilities were used, participants discussed how further adaptation was required, especially concerning the more abstract areas of social and sexual life.

"I would stress that the challenge for us is around communicating to children and their understanding is quite limited in some of their children's understanding is quite limited... their recall is limited as well so what we would say we would expect to our children is that you keep going over it again"

Head Teacher School M

Even when schools were utilising known programmes for students with intellectual disabilities, such as the EQUALS SRE programme (2010) the additional needs of those with Autistic Spectrum Condition proved difficult. Within many of the interviews, the area of greatest concern for individuals with Autistic Spectrum Condition related primarily to the social aspects of sex and sexuality. Participants reported that the more abstract areas of socio-sexual development, such as establishing and maintaining relationships, rules surrounding social media, issues relating to coercion and consent, proved problematic to teach due to the varying boundaries and unclear parameters that occur within individual social interaction.

The teaching issues were further hindered by the limited time and resources that were available for the co-ordinator to develop the necessary materials, including searching for appropriate materials and making adjustments according to the needs of the pupils. On the occasions when the role of co-ordinator seems to have been more developed and supported, the issues surrounding materials and programmes being adapted proved less problematic

“A list of differentiated learning objectives, so maybe three a sort of a low, middle and high I suppose, learning objectives and then activities around that um so all the teachers need to do is choose the objective that meets the needs of their class and then design around, their needs. So they its just a bank of activities really, really they can choose, within obviously the resources the resources that we have already got in school”

PSHE co-ordinator, School B

In addition to attempting to develop an appropriate package, interviewees discussed the ongoing changes that occurred within the schools due to individual incidents that may occur amongst the pupils. For example, the topic of inappropriate sexualised behaviour was frequently discussed within the interviews often requiring either additional material to be found or the need to revisit the topic and teach it in a different way because of the students’ processing difficulties or the way it had been previously taught.

“I think as they’re growing up and getting older and you know they see more adult film And things with sex and they get weird ideas about things They misunderstand things so you often constantly revisit things to do with relationships and appropriate behaviour”

Assistant head, School G

In some cases, further adaptation and work was reported as being necessary in cases when there was a recognition that some individuals with Autistic Spectrum Condition required additional one-to-one

intervention to ensure that they fully understood the information. This latter approach was often implemented in cases where the individual pupil had displayed either additional difficulties, such as inappropriate sexualised behaviour, or when working in groups proved difficult. Dependent upon the severity or complexity of the issues, some participants reported that such detailed work would include the involvement of outside agencies who had more experience in the realm of inappropriate sexualised behaviour, especially when legal boundaries were involved.

“Where we do have a sexual behaviour then we we would do an intervention for a particular child if they were, you know, lots of these behaviours and we would include it in a behaviour support plan.”

Assistant Head, School B

“That kind of stuff (sexting) or exposing themselves erm they might, do, well social stories around that kind of thing as well as working with you know our school police officer as well”

PSHE Lead, School I

“He (psychotherapist) will then, if it’s an emergency he will always see that child or the family support worker will know such a lot about the family, she might be able to shed some light on it.....”

Deputy Head, School C

Such one-to-one work occurred partly due to the complexities involved, but also due to the additional time required to provide a more appropriate programme which the co-ordinator struggled to provide.

“Again the schemes of work are very much just a bank of ideas I suppose, and the objectives and the outcomes, and teachers can just tailor it to their class.”

PSHE co-ordinator School B

For many of the participants, teaching the sexual mechanics was easy due to the concrete nature of the process and wide range of resources available. Often the teaching of the mechanical aspects of PSHE, including sexual intercourse, physical development and masturbation, were included within separate biology lessons, which then had to be co-ordinated with the PSHE programme.

“Well it’s taught through science as well.. the reproduction side I mean, we also do like in erm you know you start in year 2 and 3 we hatch eggs chicks from eggs, and things like that. The biology aspect of science erm is something that goes throughout the curriculum.”

Head teacher, School M

“It’s (social rules and relationships) really hard to teach it though cos so many of our youngsters are driven by rules and there are no rules in relationships, and you know there’s always differences. It’s helping them to understand that.”

Deputy Head Teacher, School D

In attempting to deal with such difficulties and so more effectively support students, participants discussed the necessity to frequently repeat and revisit topics to ensure that students with Autistic Spectrum Condition were given the opportunity to further explore and clarify the information provided.

“The idea is to be ongoing and revisit...and then add more and then revisit add more because the nature of the learning and you know you have to keep recapping the parts of the body. I mean the teachers are the judges of that and we find that.... The idea is covered.”

PSHE curriculum leader, School J

As well as repetitive exploration of issues within the classroom setting, it was reported that students with Autistic Spectrum Condition seemed more inclined to want more information beyond what was taught in the classroom than their non- Autistic peers. This often involved greater amounts of detailed questioning in order to gain further clarification about the everyday aspects of the topic.

“A child that’s got autistic spectrum condition the other day was completely confused and the mum talked to me...said he’s really confused because he he’s not sure that if you like somebody why you would kiss some people and you wouldn’t kiss others. We just did a sort of on the spot social story.”

Deputy Head Teacher, School D

Sub Theme - Services

The practicalities of both implementing and providing materials to accommodate an appropriate SRE programme frequently added further difficulties to an already difficult situation. This also placed an emphasis upon staff having to make what they thought of as a “legal” judgement in regards to whether a pupil was able to understand consent and potentially engage in an intimate relationship at some point in their life. In most cases, interviewees highlighted the minefield that the staff were confronted with in such a decision which would impact upon the level of information and teaching that took place. Concerns were raised that there were times when such decisions were potentially based upon interpretation of a situation rather than factual information. Also, the potential for an individual to develop the ability to consent once knowledge has been obtained was not considered, as many teachers focussed upon the short term consequences.

The ability and need to access appropriate support from external agencies proved, for many, to be an important element of providing a comprehensive programme. This was particularly relevant as new situations and topics arose, including legal aspects related to sexual relationships, as well as issues relating to topics such as Female Genital Mutilation, which the co-ordinators had to include but were not confident about in regards to their knowledge. Such situations would often lead to the need to access either relevant sources of information or arrange for external agencies to take the lead in such work. Unfortunately, although there were occasions when participants had successfully accessed external agencies to support their programme, often the lack of local services, particularly statutory ones, proved difficult. This would result in the need to access services from either the voluntary or independent sector resulting in additional cost which the co-ordinator would have to carefully consider in light of the limited budget available for SRE. In some circumstances, the need for more specialised input far outweighed the cost, but in other circumstances the co-ordinator had to consider whether they were skilled enough to perform the task themselves and save money. This latter approach could be successful if there were relevant, often free, materials available which the more confident staff could utilise. Even when appropriate agencies and support was commissioned, the participants were frequently faced with implementation difficulties to ensure that all relevant pupils were given the chance to access the experience. Often this was linked to some of the attitude and conflict difficulties previously discussed and many of the interviewees felt that there was a never-ending need to battle and justify the importance of SRE, particularly when planning special events involving outside speakers.

Even when such need to justify the processes did not exist, enabling all pupils to access the support could prove logistically impossible, especially if the availability of the external agency was limited. In such circumstances, the school emphasis was placed upon the co-ordinator to prioritise which pupils received the input, and this could be based upon a range of elements, including the school year in which the pupils were, in particularly if they were in the upper school, or the overall pupil needs at that specific time. For those not included, it was often hoped that both the budget and external agency would be available to facilitate a repeat.

Sub Theme - Reflection

The final accessibility issue did not directly involve pupils but centred upon attempting to ensure consistency and quality in the programme. In order to ensure that programmes being used do not stagnate and keep up with the ever changing modern world, the need to reflect upon and evaluate the approaches used in implementing such programmes is imperative. However, there were a number of participants who highlighted a lack of such processes within their schools due to a range of difficulties, including the ongoing attitudinal difficulties that were experienced as a result of senior management or external factors such as Ofsted.

“It’s that case of going to be looking into it now and looking at how people do it, trying to find ways of um kind of working out how to assess like set or evaluate how well it’s gone and what they’ve learnt.”

PSHE Lead, School A

“Being honest no (response to whether they evaluate). I mean it’s very difficult in this present climate because the focus is on the academic”

Headteacher, School L

Such reflective practices were highlighted by participants as being the only form of evaluation being utilised by the school and was frequently dependent upon observations made by staff. These observations were often based upon any changes in pupil behaviour that may have been observed by staff. However, this was often on an ad hoc basis and open to an individual staff member’s perspective and interpretation.

“I think it goes back to how we see our youngsters relating with each other boy girl relationships, how we when we talk to them about how they see women, how they see men, how they see themselves and their sexuality and their gender identity.”

Head teacher, School E

“We don’t have any official framework of evaluation, we just, I guess, it’s just kinda ongoing in talking to the students and addressing situations and looking at their behaviour and seeing how their behaviours change.”

Assistant Head teacher, School G

There were some attempts at utilising more formal assessment methods, but these tended to only explore each pupil’s knowledge post programme implementation without any pre-programme measures to compare with. Such methods also did not assess the pupil’s ability to practically utilise the knowledge gained in everyday life.

“Well it would be sort of questions and answers, or you know, matching if there’s, say for instance, something on private parts, you know, just getting them to point to different things that I’m naming.”

Lead practitioner, School N

“Each year we do the safe and well at school survey³ and we kind of follow on data on the children in terms of pregnancy which is really big for us. We also have all our inside school data, so particularly incident things are logged.

PSHE Lead, School I

³ The safe and well at school survey is an annual survey of pupils performed by the Local Education Authority in that school’s particular area looking at a range of issues, including incidents of bullying, and social media issues.

There was one occasion when such pre-programme information was obtained by a new co-ordinator, but at the time of the interview occurring no programme had commenced and so no progress could be reported. The lack of effective evaluation tool or process was reported by a number of interviewees as being a shortfall which they recognised and regretted. This regret occurred within schools where it would have strengthened the argument with senior management for more time and resources be provided an effective programme.

4.3.2.3 Over Arching Theme – Attempts to provide positive SRE

Regardless of the difficulties and barriers faced by the participants, at the heart of it was their wish to provide SRE programmes to their pupils.

Staff Competence

The role of programme co-ordinator, regardless of what the programme was called (e.g. SRE, PSHE, etc) was often taken by an individual who had an interest in the topic. To take on the role, the co-ordinator needed to be able to cope with the various difficulties faced from others, as highlighted in previous points. Regardless of the participant's overall school position, the need to adapt and negotiate was imperative. This was due to many of the issues previously highlighted concerning general prioritisation of SRE by school and individual staff having an impact upon the implementation of SRE. Often this led to co-ordinators having to plan specialist events, (e.g. visits from sexual health nurses), carefully so that they could have the maximum input whilst keeping the overall impact upon the school timetable to a minimum.

“You’re sort of put together a timetable if they come in for one day, cos you’re kind of looking at the professional’s time and sort of they come out for a day...but then you literally can’t fit all the classes in to one day. And the dynamics of the group, you can’t just put two classes together. They will not handle it.”

Teacher/lead on citizenship, PSHE and RE, School A

Negotiator and peacemaker were roles that co-ordinators frequently had to step into with regards to the practical implementation and tension that was present within the wider school culture. Often the tension was unseen but very real for the co-ordinators. This related to the pressures many co-ordinators were under as they balanced their general teaching responsibilities, including being in charge of a class on a daily basis, whilst also taking the role of SRE co-ordinator. Often the latter would involve taking time away from the former whilst the co-ordinator trained for the role or developed the programme. This would lead to the co-ordinator having to balance both roles within a limited space of time, occasionally having to delegate either task to teaching assistants.

“There are teaching assistants in the school that are very experienced and very good and they have their rapport with the students. If they are happy to do it and they work with the teacher and plan and they are confident then they would teach the students.”

PSHE curriculum leader, School J.

In most cases, these were experienced assistants but, regardless of that, not being the teacher could have an impact upon the teaching and support being provided. This was the thin line faced by the co-ordinators who were class-based on a regular basis.

Good Practice

In spite of the pressures, conflicts, and difficulties faced by participants in attempting to deliver some form of SRE, they continued to do their best. In all cases, participants were committed to providing and developing a programme. For some, this quest to develop a programme involved extensive research and training in specific programmes that were being used with pupils who had intellectual disabilities. In these instances, participants described how there was still a need for further adaptation. In the absence of any other input, there was a necessity for participants to develop new approaches and think outside of the box. Such creativity was a necessity, not just because material

needed to be further adapted for pupils with autistic spectrum condition, but because of the wide range of abilities and processing skills present amongst pupils.

“well with some of them with autism, as you know, might go well that’s that bedroom not my bedroom. So things like parents sending in photographs of public and private. So bathroom, bedroom at home, using real photographs in school, that helps and that’s a slight difference to other students.”

Safeguarding and prevention Officer, School F

At the time of the interviews occurring, there were a number of occasions when participants had reflected upon the needs of the pupils and effectiveness of the programmes utilised. On these occasions, a review of the programme was either in progress or was felt to be a necessity. Depending upon the school, such a review was possible, especially if the co-ordinator was part of or had the backing of senior management. Where such support was not present, the participant did their utmost to provide for the needs of their pupils.

Overall, the enthusiasm displayed by participants to develop a programme that effectively met pupil needs was high. In each case, the rewards for participants was being able to provide students with an SRE programme that was based upon a framework which was comprehensive and provided for everyone’s socio -sexual health needs. By achieving this, participants aimed to increase the knowledge and safety of pupils so that they could have the chance to experience effective and appropriate relationships.

“So, therefore, our aim is always to make sure how we can empower, how can these young people get the choice to say yes as well as no. So we are, well the approach I take is very much they have the same rights as everyone else and it is how we enable them to have a normal sexual relationship when they grow up.”

Safeguarding and prevention Officer, School F

4.4 DISCUSSION

The interview results have highlighted several similarities with previous studies, whilst also highlighting some new areas for consideration. As with previous studies utilising interviews (Hatton & Tector, 2010), there is a consistent recognition that the content of present SRE/PSHE programmes, even those adapted for pupils with intellectual disabilities, do not adequately meet the socio-sexual needs of individuals with Autistic Spectrum Condition. The abstract nature of the topic requires more specific teaching beyond general relationship areas, as well as not making assumptions about whether the individual with Autistic Spectrum Condition draws the correct conclusions in relation to the information compared to their neuro-typical peers. Unlike previous studies, the interview results have highlighted the impact that attitude (particularly that of senior management) has upon the ability to make such adaptations due to limited time allocated to the PSHE co-ordinator role. The limited commitment from senior management to the needs of pupils with Autistic Spectrum Condition, particularly their socio-sexual development, often led to programmes being hastily compiled in between other teaching responsibilities leading to issues surrounding consistency, staff training and/or evaluation tools for the programme. Such areas often led to difficulties in the teaching process due to the fears of staff about participating in the subject and providing the wrong information or approaches.

In contrast to the concerning attitudes present in some staff and senior management, it was reported by participants that the parental and pupil attitude toward the SRE programmes seemed to be more positive. This contradicted previous studies (McCabe, 1999; Pownall, 2010; Stokes & Kaur, 2005) which had highlighted the concerns raised by parents and pupils. There were limited reports relating to parental refusal in their child's participation in the programme, which may be an indication of general social change surrounding the issues but could also be a reflection of the cultural and religious composition of the participating schools. Similar results were present in regards to the pupils' attitudes and feelings toward the topic which was perceived by staff as being overall positive and enthusiastic.

Where incidents of inappropriate sexualised behaviour were highlighted within the interviews, there were indications of potential gaps in the knowledge base of the pupils. When such difficulties occurred, it would often lead to a more reactive strategy involving external agencies and the potential labelling of pupils as “sexually problematic”. Reflection upon these situations highlighted the inappropriateness or inflexibility of the programme, or an assumption that the pupil had understood what had been taught without any confirmation by staff.

Overall, although the study utilised only a small number of participants, the findings suggest that the socio-sexual needs of individuals with Autistic Spectrum Condition are not consistently being met within SRE/PSHE programmes being utilised by many schools, often resulting in difficulties and a more reactive approach toward the issue. There is a need to be more proactive in the realms of SRE/PSHE in order to reduce the misunderstandings that can occur in real life. Therefore, the development of a programme for pupils with Autistic Spectrum Disorder which explores the socio-sexual aspects beyond biology and focussing more on relationship building would potentially reduce the risks and mistakes that can occur. Such a programme would aim to minimise the inconsistencies in the programmes used, whilst enabling that resources (including co-ordinator time) are utilised more effectively. As highlighted within the literature review, there have been limited attempts at exploring the views of individuals with Autistic Spectrum Condition in regards to their experience of SRE/PSHE within schools. Gaining an understanding about the actual needs of pupils with Autistic Spectrum Disorder rather than making assumptions, could enable the exploration of more specific questions such as;

- In regards to SRE and general life, what areas do individuals with Autistic Spectrum Disorder actually need more support in?
- Which teaching methods and materials best suit the learning styles of pupils with Autistic Spectrum Disorder?

Such person-centred exploration would improve understanding and provide a more effective and comprehensive programme. This will be explored further in the next chapter.

4.4.1 Methodological limitations

There were a number of methodological limitations that could have impacted upon the results and subsequent interpretation. Firstly, the recruitment of adequate numbers of schools that met the inclusion criteria and who wished to participate proved difficult and was only increased through the researcher widening the area to geographical locations. This brings into question whether the results could be generalised into the wider educational arena. The issue of generalisability (Falk & Guenther, 2007) in reference to qualitative research findings has often been queried with varying views. These have included the view that qualitative research's purpose is not necessarily to generalise but inform (Myers, 2000), and also that if such results are used in a generalised manner then caution must be used in doing so, often due to limited numbers (Benz & Newman, 1998).

Secondly, the recruitment of participants and their characteristics may have impacted upon the results of the interviews. Due to the limited number of respondents and their location, factors such as ethnicity and religion were not necessarily balanced. Reflecting upon the mix of participants that were interviewed, the majority could be classed as white middle class women and they may potentially have had differing views of the subject than those from other ethnic backgrounds. This was particularly poignant considering that a small number of schools, specifically those in the London areas, had a multicultural mix of pupils and staff whose cultural and religious backgrounds were different to that of the participant. This could also have been said in relation to all the schools being based in southern England, considering that the views on sex education can differ in parts of the country such as Northern Ireland.

Finally, although the analysis of the data identified a number of themes, the analytical process was performed by an individual researcher. To have strengthened the data, it would have been appropriate to have a second researcher to also extract themes from the data. This would have enabled triangulation of the data and strengthen the validity of the resulting themes.

Regarding the schools used, the pupil skill and attainment levels were biased toward more able students and this could bring into question the ability to compare and generalise the various sex

education programmes used. This is particularly true for those schools catering for students who have more severe intellectual disabilities in addition to their Autistic Spectrum Condition and would have had a very different programme compared to the others.

Chapter Five

Study Two – The perspective of students with autistic spectrum condition

5.1 Introduction

As with many studies relating to the issue of sexuality and sex education for individuals with autistic spectrum condition, Study One has concentrated upon the views and opinions of people other than the pupils with autistic spectrum condition. Within the literature review in Chapter 3 there was only one study (Hatton & Tector, 2010) that involved a group of individuals with autistic spectrum condition who had experienced some form of SRE programme. However, this was a small scale study based upon a group of four pupils who had left the school some time previously to the study taking place. Unfortunately, even though the study discussed areas of methodology and summarised some of the results, the emphasis of the resulting article was to discuss potential procedural changes that occurred within the school rather than examining the views of the pupils involved. The methodology for the Hatton and Tector study utilised questionnaires and semi-structured interviews which provided some data but was limited due to method and participant numbers. Consequently, the qualitative data that was presented was limited to a few poignant comments made by the participants highlighting some issues raised but with limited exploration regarding the needs of pupils with autistic spectrum condition. To gain greater insight, it would be beneficial to conduct Focus Groups with a wider range of participants. Gaining greater insight from individuals with autistic spectrum condition is an invaluable step for researchers. By achieving this, it not only provides a voice for those who seek to be safe, but also gives insight to planners and teachers. The interviews in the Hatton and Tector study started this process but did not allow greater discussion. Therefore, to gain greater insight it would be beneficial to not only explore further but potentially use the dynamic and interactive approach of Focus Groups with a wider range of participants.

Focus Groups, also known as group interviewing, go beyond the intimate environment involved with one-to-one interviews, and they have been on the increase over recent years (Kvale & Brinkmann, 2009). Focus groups, as a concept and research method, were first defined by Robert Merton and his colleagues (1956) in relation to their usage within the field of social research. For many decades, focus groups were primarily used within the marketing field. However, in recent years there has been

a steady growth in the use of focus groups as part of social research (Lee, 2010). The focus group concept is based upon a group interviewing methodology where the researcher has the ability to work with several participants simultaneously rather than on an individual basis. This is performed in a “non-standard” and informal discussion (Acocella 2012). Such an approach can enable participants to more freely express themselves (Marková, 2004), including those who are more reluctant when it comes to interviews, focus groups can also enable the researcher to observe the interactional changes that can occur between participants within such situations (Crookes & Davies, 2004). Due to the nature of Focus Groups, it is potentially possible to explore a topic beyond the boundaries of the researcher’s understanding surrounding the topic (Hess-Bieber & Leavy, 2006) utilising multiple participants. In comparison to one-to-one interviews, the interactions between members within Focus Groups is fluid and dynamic in its development as it will be dependent upon the specific group. This “group effect” (Morgan 1996; Carey, 1994) is what makes the use of Focus Groups a good source of data as they provide both the researcher and participants with the opportunity to query each other and subsequently explore the issues further (Morgan & Krueger, 1993).

As with one-to-one interviews, the use of group interviews can be dependent upon the needs of the study and researcher. Although Focus Groups have been perceived as the core methodology for groups, there are alternatives (Fontana & Fey, 1994) including brainstorming groups. However, regardless of the different approaches, central to them is the ability for the researcher to work with and interview a number of participants simultaneously. With the increase in participants, so the role of the researcher changes. In contrast to the structure involved with one-to-one interviews, frequently the role of the researcher is more of a moderator and facilitator. This includes guiding the conversation to ensure that aims are reached as well as dealing with any conflicts that may arise. Although some specific questioning is required, the resulting group interaction can stimulate conversation as well as empower individuals that find intense interaction, such as one-to-one interviews, difficult. By the sheer nature of Focus Groups, the aim is to encourage and obtain such conversation within the group and so produce a mixture of views relating to the topic rather than to obtain a definitive answer (Kvale & Brinkmann, 2009). Often such enrichment of data from participants originates as much from the interaction and conversations that occur between

participants, as from responses to specific questioning (Hesse-Bieber & Leavy, 2004). The group situation can enable further exploration of those views beyond the boundaries of the questions. Such situations can provide participants with the confidence to discuss some sensitive aspects of life. An example of such liberation involved the use of Focus Groups to discuss sex and sexuality (Montell, 1995). Within her use of Focus Groups, Montell found that often the expression of an individual view regarding the subject would provide the incentive for others to open up and participate within the Focus Groups. Such interactions can also provide a safe arena within which views can be challenged, developed or even modified as the process progresses and evolves (Linell et al, 2001; Myers, 1998).

5.2 Developing Focus Groups

Utilising Focus Groups, as with one-to-one interviews, requires planning and careful consideration in regards to the various components that a researcher has to plan.

5.2.1 Recruitment

Looking at Focus Groups, additional consideration needs to be made regarding the composition and potential interaction between participants. Although Focus Groups are often formed in an ad hoc manner based upon the research need (Acocella, 2012) there is some structure needed in order to reduce potential difficulties in the discussion. Consequently, the participants recruited need to be balanced to ensure that the process involved with the group provides enriched data. In order to achieve this, the participants' demographics, e.g. cultural and social status, should not be too distant. This can assist in the discussion that occurs as the closer participants feel toward each other in these areas, the more comfortable they can feel to talk (Greenbaum, 1988). Of course, there is a need for some differing positions in order to allow discussion to occur, but the more homogenous the participant group is the greater chance there is of avoiding some participants feeling inferior to others (Acocella, 2012).

As well as obtaining an appropriate group mix, the researcher needs to ensure that they are recruiting individuals interested in the topic and similar experiences (Munday, 2006) who are able to take part

in the discussion. In order to achieve this, participants should preferably have experience and be familiar with the issues being discussed. Subsequently, this can provide the motivation for meaningful discussion to occur (Côté-Arsenault & Morrison-Beedy, 1999).

5.2.2. Environmental Factors

Before commencing with the Focus Groups, it is necessary to have an appropriate location for the Focus Group to occur. To ensure greater numbers of participants, and depending upon the source for participants, it may be necessary for the researcher to select a number of sites. For example, if the topic was school based, the practicalities involved with bringing groups of pupils from various schools is difficult, therefore it may be necessary to do a number of Focus Groups in various schools. When considering the present study there are additional difficulties concerning how the individual processes the various sensory stimuli which can impact upon their ability to effectively participate in a Focus Group. Such difficulties can include environmental distractions (for example, ambient noise, over bright lighting) which the moderator needs to consider when planning the location of the focus group, or individual issues such as the need for a wobble cushion or twiddles in order to regulate the individual's sensory situation. With such difficulties, it is imperative that the moderator is aware of such issues to ensure that appropriate advice is gained and subsequent measures are put in place to reduce the subsequent impact of difficulties.

5.2.3 Interview Guide

As with one-to-one interviews, to assist with the exploratory process there is a need for the development of an interview guide. It is recommended that such guides incorporate open-ended questions aimed at prompting the group discussion without immediately directing the process (Krueger, 1998). For the group moderator, the guide enables them to take a logical approach to the process involved. The moderator should ensure that they lead with the main questions that relate to the study to provide the participants with time to settle into the process (Côté-Arsenault & Morrison-Beedy, 1999). Once the participants have settled into the process, the conversation should become a more natural conversation with cross-conversations and challenges between participants in regards to their point of view. With the use of the right probing questions and reflective

questioning, the moderator is able to be flexible in guiding the conversation whilst remaining on task. In doing so, there is the potential for the information obtained to be an enriched mix of views, ideas and data.

5.2.4 Moderator

Although central to the Focus Group process, the questioning developed is only as successful as the individual moderating the group. This is because, regardless of how familiar participants are with each other, there is a need for guidance to ensure that the aims of any study are reached. This has been highlighted as an issue by some who feel that, even in groups comprising familiar individuals, there are group dynamic issues that impact upon the process. Particular issues relate to the fact that, in comparison to individual interviews, focus group participants need to develop, in situ, some form of common communication within a group whilst also ensuring that each individual is able to contribute to the wider group interactions (Hydèn & Bülow, 2003). In regards to the role of the moderator in this situation, it is important for them to recognise the presence of such group dynamic issues and provide guidance where required. This can further enhance, not only the experience of all involved, but also ensure that if the flow of the conversation should “dry up” then the moderator can keep it going. In performing the latter role, there is a need for balance in how involved and directive the moderator is. Wilbeck et al (2007) described this as “walking a tightrope” between the moderator leading the discussion, resulting in them being central to the process, and them remaining silent being seemingly uninvolved in the process. A balance is required between implementing a rigid structure in order to meet the specific needs of the research versus providing insufficient information and guidance resulting in a lack of data being obtained. Consequently, the moderator needs to be confident in addressing these areas in order to effectively achieve rich qualitative data for the success of the research.

5.2.5 Data Collection and Analysis

The final element when considering implementing a focus group centres upon the data collection. As with one-to-one interviews, there are various methods available to obtain and record data. The enormity of such a task, considering the potential number of sources within an individual focus group,

makes the choice of methodology important to ensure that nothing is lost. Such methods can utilise the addition of an assistant moderator who could assist in both the smooth running of the focus group as well as being able to take notes of what is happening. Alongside this, or instead of this, the use of recording equipment, both audio and visual, ensures that data can be captured and reviewed more frequently than field notes.

Upon completion of the focus groups, through the chosen data recording the researcher needs to explore the data acquired. Although some of the processes involved are similar to one-to-one interviewing, the addition of the group dynamics adds additional dimensions to the data obtained. Various approaches regarding the process have been suggested by researchers, such as Stevens (1996) who recommended that, as well as looking at the actual content of what was verbalised the researcher should examine the interactive components that occur within the group setting. This includes aspects such as recognition of dominant characters and their impact upon the views of other participants, as well as the overall interactions, commonalities and differences regarding participant views, and how conflicts were resolved within this. Wilbeck et al (2007) expanded upon this concept by considering how focus group participants' use of questioning, initially used to query views, could provide the researcher with new questioning pathways that provide additional information.

Although the interactive component of focus groups can provide additional data, there are some difficulties in being able to illustrate this in the analysis. Suggestions have been made by researchers, including utilising 'dialogical discourse analysis' (Marková et al, 2006) to explore context and consequences, or Kitzinger and Farquhar's (1999) suggestion to explore more 'sensitive moments' present within interactions. Even with such suggestions, trying to effectively capture such moments and interactions is often difficult. This is especially apparent in the reporting of results which often highlights quotes from one individual but without the context within which it was said.

5.2.6 Utilising Focus Groups with individuals who have Intellectual and developmental/autistic spectrum condition

The participation of people with intellectual and developmental disabilities in research, particularly that which is qualitative, has increased during recent years and has provided greater insight into the views and experiences of these individuals (Godley, 1996). It allows these groups the opportunity to participate in research to discuss their quality of life. Many of the approaches previously described are relevant to individuals with Intellectual and Developmental Disabilities/autistic spectrum condition and the dynamics that can develop within focus groups can assist the interactions that subsequently occur. One such benefit of focus groups for this population is the lack of need for literacy skills in order to participate which, for some such individuals, can be a barrier to other methods (Cambridge & McCarthy, 2001). However, although various elements of focus group routines and dynamics have a positive influence upon the involvement of individuals with Intellectual and Developmental Disabilities/autistic spectrum condition there are a number of difficulties that can hinder the situation.

Prior to commencing focus groups, as with one to one interviewing, it is the researcher's responsibility to ensure that consent is obtained from participants. Not only is it important to obtain informed consent from individuals with intellectual and developmental disabilities and/or autistic spectrum condition (Cea & Fisher, 2003), the process of obtaining such consent also ensures a more active decision-making role for the individual (Lotan & Ellis, 2010). As part of this process, the researcher will need to ensure that both the information and consent forms are appropriate for the individuals being asked. This should include the use of material that is accessible via appropriate vocabulary and, if required, the use of visual illustration (Rogers, 1999). Central to the processes involved with Focus Groups is the ability to communicate. However, this can frequently be a barrier when involving individuals with intellectual disabilities or Autistic Spectrum Condition. Whether it is someone with limited verbal communication or someone with processing issues requiring additional time or clarification of what has been said, the moderator needs to consider how to work with the individual. This may have to be through the use of additional visual methods (e.g. PECS or Talking Mats) (Germain, 2004; Fayette & Bond, 2018; Cambridge & Forester-Jones, 2003) or by providing

extra time, the moderator has to be able to effectively incorporate it into the Focus Group interactions whilst limiting the impact upon the overall interactions.

Although participation in focus groups can provoke anxiety in anyone who takes part due to the group aspect, for individuals with intellectual disabilities or Autistic Spectrum Condition the anxiety levels can be extreme. This can originate from the social aspect of such an approach, misunderstandings regarding the expectations in taking part and the outcomes of participation, or concerns about the personal aspects that could be potentially discussed within the focus groups. With such anxiety comes the potential for the participants' method of self-expression regarding their feelings to be negative. Therefore, the moderator needs to plan and develop appropriate strategies in order to best support each participant through the process. These can include ensuring that each individual is fully and appropriately supported in understanding what is involved with the group, as well as utilising appropriate breaks and time out throughout the focus group process. Overall the involvement of individuals with intellectual and developmental disabilities and/or Autistic Spectrum Condition in the research process, particularly in regards to qualitative studies, is a positive approach as it is important for marginalised groups to have their say.

5.3 Study Method

5.3.1 Study Aims

Primary Aim:

- Exploration of the experience of teenagers with autistic spectrum condition with regard to the present UK National Curriculum based SRE programmes that they have participated in.

Secondary Aim:

- Consider whether there is a need to adapt the present SRE programmes used with pupils with Autistic Spectrum Condition in order to encompass the areas of difficulties that are identified by people with Autistic Spectrum Condition.

- Exploration of the views of pupils with autistic spectrum condition as to whether such individuals feel that the SRE programmes experienced have effectively prepared them for the wider socio-sexual world.

5.3.2 Ethical Issues

As with any study, ethical approval was required for the Focus Groups, particularly as the process involved individuals with autistic spectrum condition who could be deemed as potentially vulnerable. The ethical approval process was similar to Study One insofar as initially this was sought from the Tizard Centre, University of Kent's Ethics Committee (See Appendix G for Ethical approval letter). Once again, due to the lack of specific educational ethical committee for local authority schools, the next layer of approval was required from the head teacher of any potential schools for the focus groups to occur. Once approval had been gained from either the head teacher or their representative, then groups of students who met the specific inclusion criteria were identified to participate in the focus groups. Due to the need for the participants to possess the capacity and understanding to be part of the focus groups, final consent was obtained directly from the students. This was achieved via a simple consent form and information sheet with pictorial content to clarify issues (see Appendix H and I). Both of these sheets were explained to the participants, rewording sentences where participants found them unclear.

5.3.3 Participants

Recruitment of participants was initially performed via the schools that had previously taken part in Study One (see chapter 4). This provided three sets of participants as remaining schools declined to participate. A further two sets of participants were accessed via an additional school located outside of the original geographical locations and which met the inclusion criteria for study One. Unfortunately, the school was unable to participate in study One but were enthusiastic to participate in subsequent studies. This additional school was located within the county of Kent and enabled two additional groups of students from its post 16 provision to participate in this study.

As with the schools, there was a need for specific inclusion criteria in regards to the participating students. This was important to ensure that each participant was able to effectively contribute to the discussion and subsequent data. Therefore, the following criteria were set out:

- Students had to have a primary diagnosis of Autistic Spectrum Condition or Asperger's Syndrome;
- Students needed to have been in the post 16 provision of their respective school to ensure that they had an opportunity to have previously received some form of SRE programme;
- Students needed to possess relatively good expressive and receptive communication skills;
- Students needed to be able to participate meaningfully in the group discussion for 45-60 minutes.

Following the criteria being developed, each of the lead staff members within the four participating schools were assigned to identify those pupils who met the specific criteria resulting in 38 participants who met the inclusion criteria. Regarding the composition of the groups, although it would have been preferable to have a mix of participants from various backgrounds and from both sexes, due to the balance of males to females with autistic spectrum condition the composition was dictated by the students available for the groups. As a result, the groups that were used comprised of the following mix:

- School 1 – 6 males and 4 females
- School 2 – 7 males and 2 females
- School 3 – 6 males
- School 4 a) – 5 males and 1 female
- School 4 b) – 5 males and 2 females

Although the gender mix was not balanced, all except School 3 had at least one female in each. Clearly this could be intimidating for the young women to be the only female in a group, so in group 4a the young woman was provided with support from a female staff member. She was also informed

that if she felt uncomfortable with the situation, then she would be able to opt out of the group but would have the opportunity to contribute on a one-to-one basis with the researcher.

In addition to the pupils, within three of the focus groups, some school staff were present. In the case of School 2, the staff were the Head of Key Stage Four (the stage each pupil came from) and the SRE Teacher. The reasoning for the staff being present related to safeguarding issues as the researcher was not previously known by the school, as well as the staff being present to assist with any issues that may have arisen. From the beginning, the staff reassured pupils that they could talk openly about the topic without any perceived consequences even though the staff were present. Such reassurances may have reduced the impact of the presence of staff during the focus groups, although it cannot be certain. Regarding the two groups from School 4, the staff member was the Post16/SRE co-ordinator. The reasoning for her presence was to support students to participate due to issues of anxiety. As with School 2, the students were reassured that they could be open and honest. In both schools, it is hard to be sure whether the staff being present had a definite impact. In contrast, in both Schools 1 and 3 no staff were present but they did know the primary researcher from previous work that had occurred. This familiarity may have impacted upon the discussion within these groups as the students potentially felt more relaxed, due to having met the researcher before and/or not feeling restrained by their teachers' presence. This may have resulted in a richer discussion occurring with greater detail being obtained.

In all cases, the degree to which the highlighted staff elements had an impact upon the results can only be speculated upon from the data obtained. As the analysis will demonstrate, regardless of the situation, useful data was obtained to explore the themes and situation. Across the groups, many of the identified themes were similar regardless of whether teachers were present, especially concerning programme content and teaching methodology.

5.3.4 Consent

Regarding consent from the schools, as with Study One, the primary staff contact was provided with information (See Appendix J) regarding the focus group aims and processes. Consent was then

obtained from schools in relation to their participation through written confirmation (See Appendix K) and their active participation in planning the focus groups. Also, parents of prospective participants were notified about the study and relevant information provided (see Appendix L and M).

Before the groups commenced, as with any research involving individuals, it was necessary to gain consent from those individuals involved. In relation to the present study, a consent form was specifically developed for the study along with an information sheet regarding the study (See Appendix H and I). Both documents utilised unambiguous and jargon free language which was reinforced with appropriate pictures. This combination enabled potential participants to more easily access the information.

In addition to the documents, both the researcher and relevant school staff talked to the prospective participants regarding the study; including the reason for the study, the rationale for using focus groups and the role the participants could potentially play within the process. The individual could make the choice to participate in the study. As well as the consent form, if consent was obtained, at the beginning of the focus groups the researcher repeated the rationale and aims of the focus group and study to ensure any final questions were answered. This also provided participants with the opportunity to withdraw their consent and their participation, reinforcing information already provided. Additionally, the researcher clarified issues regarding confidentiality and the information obtained within the focus group, as well as reminding participants that the focus groups were not compulsory and that they could withdraw from the process at any point (Owens, 2001). Participants were informed that should they have any difficulties relating to the study, there was a complaints process that could be followed. All except one student continued with the focus groups. This particular student had become highly anxious prior to the group occurring, although it is not known whether this was due to the focus group topics, process, or some other factor.

5.3.5 Process of the Focus Groups

Once consent was obtained from all involved, the focus groups were planned. Each group followed a similar pattern to that described in the literature (Côté-Arsenault & Morrison-Beedy, 1999; Hydèn & Bülow, 2003; Wilbeck et al, 2007) In each case, the groups occurred within the respective school's environment in a room chosen by the lead staff member as being appropriate to the situation. Prior to the groups commencing, a set of broad questions was compiled, similar to an interview schedule, in order to provide guidance where necessary. These "umbrella questions" included:

- Tell me about your experience of sex education in school.
- When did you start having sex education?
- How long did you have sex education for?
- What was the best way you learnt?
- Do you feel that the sex education you received was enough to keep you safe?

5.3.6 Data Collection and Analysis

As there was only one researcher involved in the focus groups, data collection was performed utilising note taking, audio recording and video filming. Utilising these methods together ensured that conversation amongst participants and subsequent data were not missed, whilst also enabling the researcher to focus more on the interaction and conversation occurring within the group.

As with the data in Study One, the analytical process involved a thematic analysis approach. The implementation of the analysis took a similar three-stage process to that for Study One (Creswell, 2007) with one difference. Due to the interactive nature of the Focus Groups, as well as the number of individuals involved, there was the addition of a video camera. This was used to back up the oral recordings as well as enabling an examination of the interactions that occurred within the sessions and which may have had an impact upon the situation. Therefore, the processes involved in the analysis followed the same stages as Study One: data preparation via transcribing, thematic analysis of the data and presentation of the data. However, the difference in the process for the Focus Group analysis involved each group transcription being repeatedly read alongside first the audio recordings

for accuracy and then the video recordings for any significant interactions. Once the review of the transcriptions had been completed, a more detailed exploration of the data occurred in order to identify primary overarching themes (Guest et al, 2012). Again, it could have been beneficial to have had a second coder to analyse a percentage of the transcriptions that resulted from the focus groups, but due to the rigid time constraints this was once again difficult to achieve. In contrast to the interviews (Chapter 4), the Focus Groups did provide an additional element to the analytical process in the form of both transcriptions from audio recordings and also video recordings. Although the results from both methods were once again inductively analysed by one individual without any predefined coding scheme, the use of two recording methods provided an element of data triangulation due to the utilisation of two differing perspectives of the same data.

As with Study One, further analysis of the data identified subthemes from repeated key concepts that occurred throughout the Focus Groups (Braun and Clarke, 2006 p82). Each of the themes; both overarching and sub, were reviewed on a number of occasions to ensure appropriateness. Figure 5.1 outlines these themes.

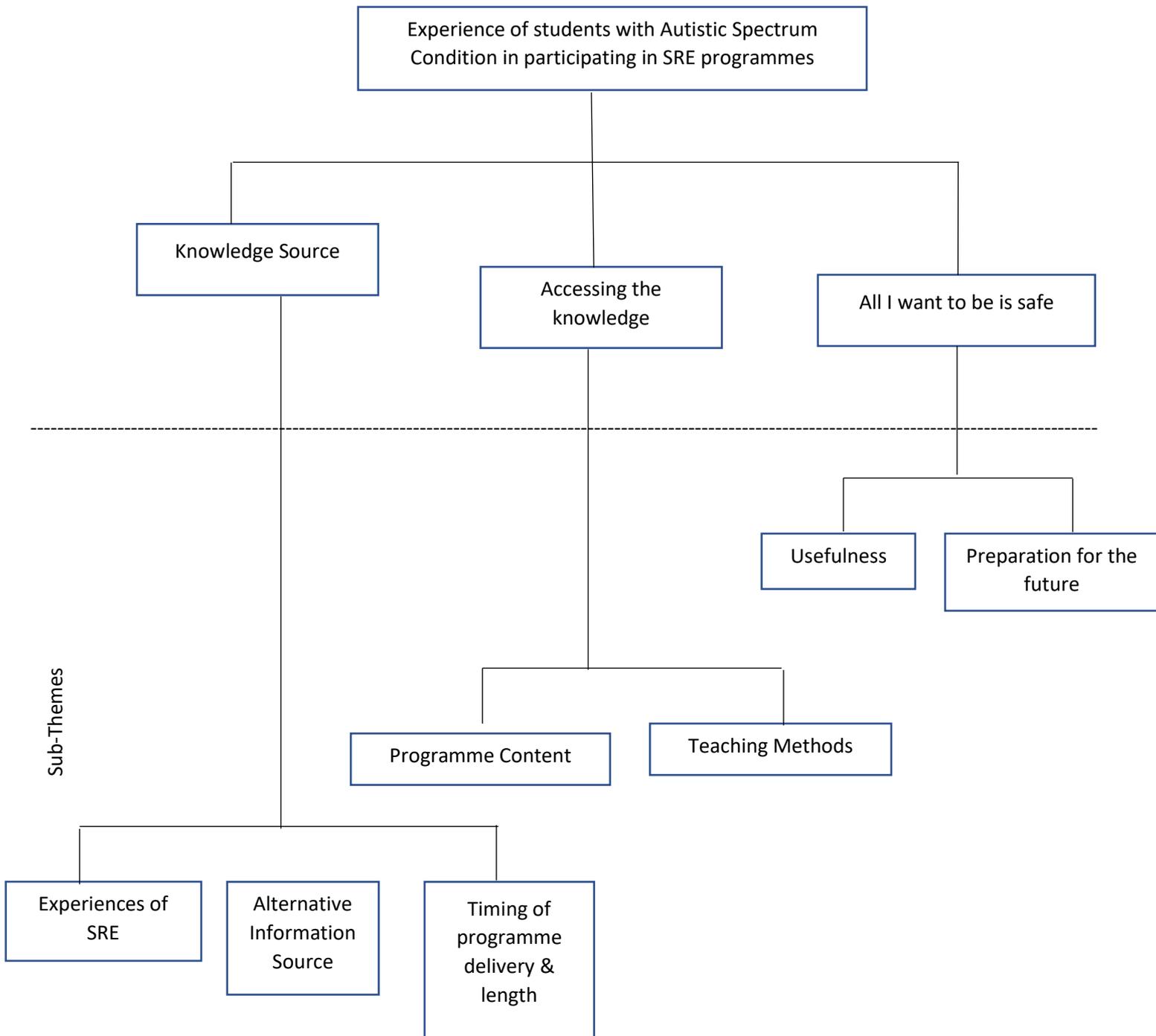


Fig. 5.1 – Focus Group Themes

5.4 Results

As highlighted, there were three main overarching themes each with their own set of subthemes, and there was a general feeling of frustration experienced by many of the participants regarding

difficulties in the implementation of an effective SRE programme with the pupils in their schools. This frustration occurred throughout the resulting themes demonstrating a number of shortfalls in the SRE support and knowledge being provided to the participants.

5.4.1 Over Arching Theme – Knowledge Source

Within the Focus Groups discussion took place regarding the experiences of SRE prior to entering the post 16 facilities. This highlighted inconsistencies in the implementation of SRE programmes across the schools often resulting in participants trying to fill the knowledge gaps that were subsequently present.

Subtheme – The experiences of SRE

The inclusion criteria for participants in the Focus Group only specified those in post 16 provision as there was an expectation that every individual would have received some form of SRE within a school situation. Unfortunately, this proved not to be the case, which resulted in some participants feeling extremely frustrated and unprepared for the socio-sexual world around them. Within the groups there was a mix of experiences between mainstream⁴ and specialist schools, although the latter category of schools was more prominent, often because participants had been at the school for several years. In all cases where participants attended a specialist school, they had received some form of SRE. In contrast, those who previously attended a mainstream placement were confronted with a mix of support.

“Yeah, there's the-- basically I didn't get much detail in year six, that's because it was a mainstream school.”

M2, School 2

The frustration shown was primarily from those individuals who had transferred from another school in order to access the specialist post 16 services, and the topic was discussed within four of the five

⁴ None of the current schools included in the study was mainstream, but some pupils had previously come from mainstream schools

groups. Frequently the individuals concerned had come from a mainstream school setting where the general support provided was no longer adequate for their needs, including the socio-sexual aspects via SRE programmes. Concerning the SRE aspect, often these seem to have been non-existent as a formal programme in many cases, with participants describing how they did not have any recollection of receiving SRE even though they felt that others in their old school had participated in such lessons.

Frustration regarding previous experiences of SRE was, in one case, not due to the lack of SRE programmes but related to the ethos of the school. In this case, the difficulty was with the implementation, since it was religiously based. The participant (F2, School 1) described her experience of attending a faith-based mainstream school which meant that, although the SRE programme explored the biological aspects, including body parts and the “mechanical” aspects, it was accompanied by a curriculum that heavily emphasised religious views concerning the sin of sexual relationships outside wedlock and the benefits of abstinence.

“So we had to learn the parts and then we learnt about some types of contraception and how fertilisation happens but we didn't actually learn anything about the process we were completely told off of it, we weren't told what condoms are or anything like that.”

F2, School 1

During the discussion, other participants highlighted the unfairness of such an approach, whilst the specific participant described how any discussion surrounding contraception and sexually transmitted infections was used more to reinforce the abstinence view rather than to equip an individual with autistic spectrum condition for the socio-sexual side of life.

Although the majority of participants did receive some form of sex education, there were still difficulties regarding the actual content of the teaching. In most cases, the biological aspects such as body parts and conception were felt by participants to have been appropriately taught using visuals and videos. Such discussions also highlighted how the issue of contraception was demonstrated via specialist equipment. However, in many cases the socio-sexual aspects were not perceived as being effectively discussed. This meant that the discussion relating to friendships, relationships, sexuality

and even consent, were either perceived as being non-existent or inadequate for the needs of some participants. Consequently, for many the need for information to fill the gaps led them to seek out other sources of information.

Subtheme - Alternative information sources

As with Study One, participants in Study Two expressed a level of frustration with the SRE programme. This frustration was linked to the distinct lack of comprehensive knowledge within the programmes being delivered. This resulted in all the focus groups, even those that felt they had been provided with a degree of knowledge, discussing how they felt there were gaps in their knowledge. Often this led to some participants identifying shortfalls in their understanding of boundaries and law. The resulting frustration expressed by participants meant that they had to look at accessing various alternative sources, many of which were unmonitored. Amongst the groups, a variety of alternative sources were accessed, although generally it was the more easily accessible sources such as the internet and peers which many utilised. Unfortunately, both these sources prove problematic and often resulted in misinformation.

“My parents did tell me a bit like you know you know some bits that school told me some things that school didn't tell me so that was quite helpful. My brother did also told me quite a bit about it as well. And you know like doing a bit of research on the Internet that did a bit of help as well. “

M5, School 3

!Yeah, yeah I would agree with that. For also I do think like, like cos I I learned some stuff from my mum as well cos I have an open relationship with my mum but I haven't always had that kind of relationship like when I was younger if I gone and mentioned to her like something like about like something like porn and that she would have been really angry with me and not really like I don't think she would have necessarily understood and like so I just didn't mention it I just assumed like that was the way it was or something.”

M1 School 2

When discussing the use of the internet, participants recognised that although the internet could provide a wide range of information, it could also provide inappropriate knowledge. This was particularly true with regard to adult pornographic material with some participants recognising the inappropriate and coercive aspects regarding relationships. However, for some of the other participants these were seen as a primary source of information.

“I think pornography misdirects a lot of people into what sex is really like.”

F4, School 2

Although the emphasis of the internet discussion centred upon it being a source of information, as with many teenagers, the participants also talked of their usage of social media. For many participants there was a perceived level of peer pressure to be part of the social media arena, especially as a way to be potentially liked by others. Unfortunately, this was for some done without the normal social boundaries and parameters surrounding appropriate friendships/relationship forming.

“I think it would be useful especially with this generation to learn about the legal ages earlier in life because you know you keep hearing stories about like 13 year olds that get pregnant somehow and it's because they haven't been more and more younger and younger people are on the Internet and that's not always a good thing. Because they can stumble across inappropriate things and not know the extent of, of like what that means and what's good and what's ok and what's not ok so I think that could be useful to learn.

F2, School 1

Such experiences do not necessarily reflect the reality of life and face to face experiences. Yet an alternative source of information, peers and peer pressure could also prove problematic and lead to an individual engaging in inappropriate situations. For many, the difficulties with peers centred upon the fact that many of the participants' peers often had deficits in their own knowledge and

understanding. Consequently, all involved were trying to fill the gap, often unsuccessfully. This was highlighted within some of the focus groups as many were friends and so would discuss and explore various socio-sexual issues amongst themselves regardless of their levels of understanding. Regardless of how incorrect the resulting information might be, using the internet and peers as information sources was frequently more easily accessible than the alternatives. This reduced the immediate frustration felt by participants concerning the perceived gaps in information provided by schools. Unfortunately, in the long-term filling in information using these sources caused further frustration which will be explored later. In contrast, the use of appropriate external professionals was identified by some as a more reliable source of information. In some cases, accessing such professionals occurred within the school setting as part of the SRE programme by inviting professionals to lead specific sessions such as contraception and sexually transmitted infections. This mirrors previous comments in Study One about accessing professionals. In one school the involvement of a professional was based outside of the school via visits to local clinics, which often enabled participants to experience the teaching within the real-life situation. This latter, more practical approach seemed to result in a greater retention of knowledge by the participants who were able to recount a range of items discussed. However, within that there were still limitations regarding the information provided as its focus once again was on the practical aspects of birth control and sexual health.

“I know the school nurse did was the one who taught me about my public places and my ...my public and my private places and public places.”

M4, School 4b

In the absence of other sources, many participants sought information from within their own family setting, including both parents and siblings. Often these discussions were extensions of what had been taught at school or at a time when the participant need to explore an everyday situation such as friendship/relationship issues. Considering the nature of the discussion, it is surprising how for the most part, adolescent participants across the focus groups felt comfortable to discuss such personal issues with their family members. Unfortunately, although this provided an additional source of information, discussion within the focus groups highlighted how in some cases this was not

always reliable. The benefits of such discussions between family member and child depended upon the embarrassment levels of both parties, although primarily that of the family member, the family member's own level of knowledge, as well as the nature of the knowledge being requested. When the discussion involved talking with parents about more "modern" topics such as the internet and teenage interactions difficulties arose depending upon how up to date parents were regarding the internet and the teenage culture compared to when they were teenagers. Difficulties with siblings providing information was similar to those of peers as the information provided was dependent upon the sibling's own education. Consequently, as with other sources, often participants were faced with variable levels in the accuracy of the information being provided by family members.

"You going to need to like get like information from your parents, your family members, outside community, online so I think outside like a bit of both really did also help."

M5, School 3

"I need to find one, well cos my dad said to me there's always time SD anyway cos you don't have to have a girlfriend till late really."

M2, School 3

"I think we should learn about different people's attitudes towards sex cos obviously... not everyone's parents are open etcetera."

M1, School 1

Subtheme - Timing of programme delivery and length

For participants, further frustration was shown concerning when and how long SRE programmes were being implemented by school. The majority of participants recalled having SRE lessons during the upper years of secondary school life, but very little if any such education prior to the age of 14/15 years (School Year 9). This lack of SRE prior to this time, in some cases, may be a true reflection of the situation or that the lessons they had received earlier on in their school life were not memorable enough for them.

“So it was kind of at the last minute it was like the last couple of weeks of year 11.”

F3, School 4b

“Well I probably started learning it about when I was 16 really. Well when I was doing secondary late secondary.”

M2, School 3

Receiving SRE after participants had already commenced puberty and their socio-sexual interaction proved frustrating for many. For some, particularly the girls, discussing issues relating to physical development at this age meant that many participants had been forced to navigate the minefield that is puberty without the appropriate knowledge or support. For girls this meant not understanding the full consequences of having periods, for boys the understanding about erections and wet dreams, although in some cases these topics were not discussed in the present SRE offered.

Additionally, participants discussed how some of them and their friends had already engaged in having relationships, accessing pornographic material and some displayed potentially inappropriate behaviour which may have resulted in some reactive discussion, prior to receiving formal SRE. This caused participants to become frustrated as they felt that the teaching should have occurred much earlier in order to prepare them for all aspects of their development. For some, they felt SRE programmes should have commenced within Primary School especially as they had made attempts to develop friendships which unfortunately failed.

“Because I was, I've been bullied literally in primary school and secondary school, and I think it probably would have helped to learn...a lot younger about relationships and why people act a certain way.”

F1, School 1

“I do think I do think we should have been taught some safety like in regards to like the fact that like girls shouldn't like use a public toilet at midnight because that's bad, that kind of thing. And like do you cos it puts them. How to like not put yourself at let how to put yourself at less risk.”

M1, School 1

In some instances, this would have enabled participants to possess the knowledge to make appropriate choices about socio-sexual encounters and experiences that they have been confronted with. In addition, to the actual timings of when such programmes occurred, there was a feeling from participants that even with the SRE programme in place, their ongoing socio-sexual development and experiences was an ever-changing entity which required support and assistance. Not only would this ongoing intervention and support guide the individual through their development, but it could also take into account the individuality of each participant.

This need for ongoing support in order to help appropriate development was present in most of the Focus Groups. For many participants, it seemed that the SRE programmes being provided were time limited or performed as a reaction to something that had happened within the school environment. This led to participants receiving short programmes, sometimes tailored to specific aspects of their development but with no ongoing teaching occurring to more fully explore the topics. Even where one school involved had a “structured and timetabled PSHE”, participants felt that it was too short and did not enable them to explore and discuss issues as the programme was only delivered over a few weeks, generally within half a term, but with no follow-up. Generally, participants in all the Focus Groups felt that to ensure they had received the appropriate information and support, as well as to have the opportunity to explore topics in enough detail, the programmes should have been longer. Many felt that this should have occurred as an ongoing process throughout their school life.

5.4.2 Over-Arching Theme - Accessing the Knowledge

Regardless of what age the SRE programmes occurred or how long the SRE programmes went on for there was no guarantee that the participants effectively gained the skills and knowledge necessary

to develop appropriate relationships. The acquisition of knowledge was dependent upon two important elements: what is taught and how it is taught. Absence of any of these elements meant frustration for participants. In both cases, it was expressed by participants that regardless of whether they received a structured SRE programme or not, if the content and teaching methods were deemed inadequate then the greater chance of participants becoming frustrated.

“and they made us do like worksheets and stuff which I didn't like cos it, it just felt like a bit babyish like... Yeah it was about the worksheet we done was like where you have to the teacher cuts up some pieces and you had to like put them on to this piece about whether you no hang on it was we sitting in a circle right sorry I got it wrong we were sitting in a circle and we had to like unfold these pieces of papers and its said something and it was like relating to like internet sex like porn... and like nudes and that kind of thing and it was like should you do this yes or no and you had to say why and it just felt like. I just thought they could have been telling it telling us maybe in a PowerPoint with some bullet points or something.”

M1, School 3

Although participants displayed frustration, there were occasions when good memorable teaching was highlighted and added to the overall discussion.

“Just cos like my teacher explained it in a way that was quite you know in a way that was easy to understand. And the pictures were very easy to understand as well.”

F3, School 4b

Subtheme - Programme Content

Potentially the most important aspect for participants was the information provided within the programme. Participants identified two main distinct knowledge groups, biological/mechanical aspects and the socio-sexual/relationship aspect. Regarding the former, frequently the discussion

amongst participants highlighted the ease with which the foundation information was consistently provided throughout each school. Such information focussed purely upon the biological and mechanical aspects of SRE and could be taught either as part of the SRE programme or within separate biology lessons.

In my mainstream school it (sex education) was literally just a specification. We in we learnt it through biology. So we had to learn the parts and then we learnt about some types of contraception and how fertilisation happens but we didn't actually learn anything about the process we were completely told off of it, we weren't told what condoms are or anything like that.

F2, School 1

Teaching within the separate biology lessons often caused difficulties for some participants as they discussed how on occasion, they would receive duplicate information about this aspect within both the SRE and Biology lessons. This caused frustration amongst participants as it was felt that these sessions took up valuable time which could have been channelled into other more complex areas. In some instances, participants felt that this demonstrated a lack of discussion between staff, potentially highlighting a lack of commitment from school in assisting participants.

When discussing the content of any of the programmes provided within the schools, participants placed a significant emphasis upon the wider abstract area of friendships and relationships in the context of the changing modern world. With the fast-paced nature of the modern world, for many individuals, being able to keep up with expanding social boundaries and etiquettes was difficult without appropriate guidance. Without such guidance, the potential for inappropriate social acts and responses were increased and had resulted in some participants making such mistakes. During the Focus Group discussions, the one constant factor that participants indicated across the schools was the inadequacy and inconsistency of the teaching in this subject. Participants indicated that the teaching of the socio-sexual aspect of SRE ranged from it not being addressed at all, to a programme that had been developed by a team aimed at covering a wide range of socio-sexual topics. Although this latter group felt that the developed programme covered a wide range of topics, including abusive relationships, sex and the law, and sexuality, the opinion from participants was that the time

allocated to implementing the programme was not long enough for in-depth discussion to occur and so they felt that although the information had been provided putting it into context was difficult. Where less detailed teaching was utilised, this was often superficial at best, for example one participant being taught only the basics with an emphasis upon abstinence and avoiding any form of intimate relationships.

“Yeah we did something about it was relationships but we didn't really go into any real depth into anything like that one week it would be unhealthy and healthy relationships.”

F1, School 1

This proved frustrating for many participants as it was often felt that without the potential to obtain the knowledge, put it into practice and then review the effectiveness of subsequent interactions participants would not be able to effectively develop their skills. Consequently, participants felt that the only time their knowledge and skills would be measured is when they would be faced with actual real-life situations which would require such additional skill and knowledge.

The deficits in knowledge, particularly the socio-sexual aspects, became apparent when, as part of the Focus Groups, participants were asked a range of questions to gain some indication of their knowledge. Initially, participants were able to answer the questions that related to foundation knowledge, such as body parts, etc, however the responses to more abstract socio-sexual side was varied between schools. Frequently, the need for additional information was based upon topics related to incidents that had occurred within school. This was particularly true concerning internet safety and gender/sexuality issues. The former issue was reported by two focus groups who were aware of incidents that had occurred within the school of pupils sending inappropriate texts (sexting) to others and resulted in specific mini programmes relating to internet and technology safety. The latter issue of gender/sexuality was highlighted in detail by one focus group and which had been introduced within the SRE programme following a number of potentially homophobic incidents. The participants from each school involved were indicating that the inclusion of such information was a knee-jerk reaction to the incidents but had led to each topic then becoming a more permanent part

of the SRE teaching programme. However, some participants did recognise and discuss their feelings that the incidents could have been avoided if the school had been more proactive in their approach to the situation.

Subtheme - Teaching methods

Throughout the Focus Groups, participants frequently highlighted the need and importance of knowledge. However, this turned into frustration due to the teaching methods being utilised within the schools not necessarily being effective for the wider socio-sexual issues of the world. Consequently, participants recognised that the need for more effective and appropriate teaching approaches was imperative. Unfortunately, from the perspective of some participants access to appropriate teaching methods was limited. This proved particularly frustrating and difficult for many of the participants, especially those who were enthusiastic to gain the knowledge and relate it to their own lives.

“Like like I said you're not going to get like all the information you are going to get like from school. You going to need to like get like information from your parents, your family members, outside community, online so I think outside like a bit of both really did also help.”

M5, School 3

Although, as with any group, the learning styles within the Focus Groups was varied, as part of the discussion participants did identify a number of common methods that fitted with many people's learning styles. Often participants found that formal lecturing about the socio-sexual world was too rigid to enable relevant discussion. In contrast, participants seemed to benefit most from less formal methods than just being lectured to, such as the use of educational films, demonstration, and group discussion. Participants felt that possessing the opportunity to discuss and analyse the various complex aspects of the socio-sexual world was pivotal in the development of participants skills to have safe and appropriate relationships. However, although this is a good approach to use, it is important to get the group size right. One school's approach was to have a large group of mixed ability pupils. Unfortunately, this was not conducive for proper discussion to occur as some pupils

found it intimidating and did not contribute. The lack of opportunity for some to effectively participate in the conversation proved concerning for the participants as many involved with this group were in relationships or had been in relationships which had failed due to not understanding the finer socio-sexual aspects of life.

“Um kind of unsettling tone of overcrowded probably hard to get a breath out, every guy from FED (Further Education Department) in the same classroom but and I don't really think it would be like not me but a lot them won't really like you know, get the same thing as the rest of us will.”

M5, School 3

Visually, many participants highlighted how educational films, particularly those portraying scenarios that demonstrated socio-sexual areas of life, was the most beneficial. Participants described how by being able to observe such interactions it allowed them as a group to analyse and discuss as a group of individuals with varied experiences what they had observed. Consequently, this provided everyone with various views and options enabling them to clarify what they had observed, which in turn enabled them to develop potential coping strategies for the real world. For many participants, this approach was felt to be more productive and useful than someone lecturing to them about what could be done. Unfortunately, although participants found this approach useful and less frustrating, there were still inconsistencies in how it was managed. Participants much preferred to have such discussions within small groups, especially as some individuals were more confident than others which could lead to others not being able to contribute.

“When we were in Year 11 my class and the other class altogether had like sex talk and I know that we we were learning like the parts and say if we knew them and what we knew about them and talk about what they were about...But it was the whole year and there were to many people in it... It was too crowded with all, you know big class with my for the whole Year doing it together.”

F3, School 1

This was demonstrated within one of the Focus Groups within which one particular participant who was very confident about talking, would often either attempt to lead the conversation or verbally

push others into contributing. Additionally, the students from this particular school talk in detail about how they felt that frequently the use of worksheets within the SRE programme seemed babyish and often the teaching was not necessarily geared up to the socio-sexual side of life but to more general life issues.

“and they made us do like worksheets and stuff which I didn't like cos it, it just felt like a bit babyish like.”

M1, School 1

The issue of worksheets was also highlighted within another Focus Group who felt that they were boring and not necessarily relevant to the topics being discussed.

On the positive side, participants across the groups found the use of PowerPoints useful if, once again, linked with discussion and often humour. This use of a visual aid, as with videos, was unanimously welcomed as it provided the participants with more memorable information than just being taught.

“I'd say pictures and talking was the most useful. Just cos like my teacher explained it in a way that was quite you know in a way that was easy to understand. And the pictures were very easy to understand as well.”

F3, School 4b

This also included demonstrations of tasks such as use of contraception.

“And he showed us a model of a penis for example, and he showed us how to put a condom on it.”

M4, School 2

When frequently repeated with the groups, whether on a termly or yearly basis, such approaches further reinforce the information and approaches utilised.

5.4.3 Over-Arching Theme - All I want is to be safe

For many participants, the ultimate aim of having SRE programmes was to enable them as individuals to possess the skills and understanding to keep themselves and others safe. This necessity and wish was high on the participants' lists but very reliant upon the effectiveness of the programmes being used.

Subtheme – Usefulness of the SRE received

Throughout the Focus Groups, the discussion surrounding acquired knowledge was ongoing. As has been previously mentioned, it is often the more abstract socio-sexual aspects of life that is the hardest to teach, particularly concerning relationships. As young adults/adolescents, knowing how to develop and maintain relationships was very much a priority for the participants in the Focus Groups; both friendships and more intimate relationships. The support received by many was felt to be inadequate for their needs.

“Yeah we did something about it was relationships but we didn't really go into any real depth into anything like that one week it would be unhealthy and healthy relationships.”

F1, School 3

“So yes so it's not such school that you know told me a lot about you know relationships but as like around the community as well. I just did because like because there was nothing really else for me to do so I was just literally like you know I should probably do some research”

M5, School 3

Even during the interactions that occurred during the Focus Groups often the deficits in relationship skills became apparent. This could be observed between participants when what was thought to be just innocent “banter” by certain individuals, actually turned into something more negative due to misunderstandings by others. This would include inappropriate comments being made followed by

a period of “repair” by all involved to reduce any damage caused by the interaction. Although not every single situation or socio-sexual difficulty can actually be dealt with due to the fluid nature of this area, an effective SRE programme should provide the foundation knowledge from which an individual can build upon.

“F1: Not in the idea of like what to do if someone comes up to you and is trying to trying to have their way with you. How to like push them away word wise instead of having to use physical attributes like like pushing them away.

F2: I know a few tips online.

F1: But because if you do that that could actually be classed as abuse, and its, its just its either you just let it happen or you push it away because of you don't know any other way to like if someone comes and tries to chat you up and you're just like go away but you don't want to hurt them so you want to say it in a different way.

F2: Try to stay pacifist, but also be assertive just be like no.”

School 3, participant conversation

Subtheme – Preparation for the future

The results of Study One discussed how evaluating SRE programme proved difficult, especially in relation to the more abstract aspects of socio-sexual knowledge. The feedback from the Focus Group participants seems to reinforce this issue. Primarily, the only time that an evaluation of the programmes and knowledge acquired by participants was performed the focus was more on the concrete knowledge. Unfortunately, this meant that the more abstract aspects of socio-sexual knowledge and a review of the overall effectiveness of the programme implementation was not achieved. Therefore, for many participants there was not chance to demonstrate their working knowledge or clarify any potentially gaps.

"We had it once following like one of your talks, no one else that is in this room was there. Because it was just for like for R's class they boys in me and R's class but N basically done like a thing were we could ask any questions and stuff and I don't think he knew all question and things like I don't think he knew everything and was a very knowledgeable about himself so I didn't think that I didn't think that was good at all personally."

M4, School 3

As such, being part of the Focus Group was for some the first chance that participants had to feedback about the SRE programmes. Overall, the general consensus was that the SRE programmes had not been sufficient for participants' needs, especially with regards to more abstract aspects of SRE which required more detailed exploration. When exploring the idea of relationships and the teaching provided by schools, participants expressed their concern and dissatisfaction. Central to this seems to have been the fluid nature of relationships which makes normal teaching difficult. When attempts had been made to explore relationship issues these were often done in an ad hoc manner, and usually in response to an issue that had arisen. This meant that no specific time was allocated for such areas and meant that the information provided was frequently superficial. Often it was felt that this led to gaps in their understanding and knowledge acquired via the programme. One group (School 1) of participants discussed how they felt frustrated and disappointed by the teaching.

"I must say building up on the friendships and relationships one thing we've learnt very very little or we have touched up on but learnt very little about is like gay relationships and open relationships etcetera. I just don't feel we learnt enough about it given about how much it's accepted and normal in this time."

M4, School 1

This primarily related to the lack of discussion surrounding two specific areas; accessing online pornography, and sexuality and gender issues. Both of these were poignant at the time as there had been issues with students accessing pornography as well as difficulties relating to an individual

exploring their sexuality in inappropriate ways which triggered some homophobic bullying due to others' misunderstanding. The group discussion highlighted how the teaching, had been impacted upon by the views of the staff leading the teaching who felt it inappropriate to talk about certain subjects, e.g. pornography, potentially due to their own feelings or the perception that it was inappropriate to teach the subject to students.

“There'd be less homophobia if it was considered like if it was talked about the same as like heterosexual relationships, I, in the talk that you did it, it wasn't like bias or hetero-normal normalising or anything that was good, but some other things like when they're taught, teach younger audiences about this kind of thing they don't really touch on sexualities and, and that's not very good cos it can lead to like homophobia cos people aren't educated.”

F1, School 1

This latter aspect is potentially about having to discuss a topic with students who are underage, but, as identified by the group, when it is recognised that many individuals have often accessed such materials under the legal age then the absence of such discussion ignores the reality of the world.

In contrast, the more logical and concrete topics relating to law, public and private, etc were given more time. This enabled the participants to gain some understanding surrounding the consequences to an individual's actions, as well as recognising when they were at potential risk. However, although the retention of the information had been successful, as indicated by some limited questioning by the researcher, putting this into more practical aspects was not so successful. This led to many participants still being vulnerable. Where participants recognised the problem between concrete and abstract knowledge, they felt that school should have provided a formal relationship programme. Such a programme would, as discussed by participants, enable more open exploration regarding relationships resulting in building the links between all aspects, thus reducing people's vulnerabilities.

“F2: Do you know what else would be sort of useful and I know I think, I think there's probably already been touched on because you know the whole consent thing it can go two ways learning about how or teaching the potential victims, like how to protect themselves but also teach the the potential like attackers not to do that. And what's not ok. And like people aren't.

M1: It's not really like that.

F2: I, I don't know. I don't think I'm explaining this right.

M1: People, I must say, people are like taught to steal not to steal from a young age but people still steal anyway like.”

School 3, participant conversation

The only contradiction to the general view regarding the usefulness of the SRE programme came from School 2 where the pupils felt the information provided was adequate for their needs, although this was dependent upon the member of staff leading the SRE session.

“He's (teacher) very understanding and very gentle when he talks to someone. I don't know, you asked me. He speaks to you, like respect. He respects us and we respect back. He's got a way of talking to us very nicely to calm us down when we're angry or upset or we don't understand, he can explain in his special way of explaining things and we understand.”

F1, School 2

This was the only school to provide some form of “formal structured” SRE programme, as well as the head of year being present during the actual Focus Groups.

5.5 Discussion

According to government legislation, every local authority maintained school in England is obliged to teach SRE from age 11 upwards. However, how SRE is implemented is left to the individual schools. Frequently when there are gaps in an individual's knowledge, regardless of the topic, people will attempt to fill that gap from other sources. Without appropriate guidance, such sources can provide misinformation leading to incorrect knowledge and interpretation. In relation to the topic of SRE such difficulties can lead to individuals not possessing a full understanding of boundaries and the law, e.g. consent, which potentially places them in contact with the Criminal Justice System. This is further impacted by the differing boundaries and rules relating to the internet. The internet, although a great tool for people to utilise for seeking information, communicating with others, making shopping easier, has some problems: the issue of "fake news" or incorrect and unmonitored information can cause more difficulties, especially for those who may interpret the world in a literal fashion such as some individuals with Autistic Spectrum Condition. Regarding SRE and the socio-sexual aspect of life, an individual is faced with all manner of indicators as to how a relationship may progress. This may involve accessing adult pornographic material (which can display coercive behaviour shown in order to develop a sexual relationship), or information that is biased to an aspect of relationships (e.g. Abstinence-only sites), As well as using the internet to access specific information, the escalating use of various social media sites provides a source of social experiences as well as knowledge. Peer pressure and the need to be liked by as many people as possible can lead some individuals to ignore normal social boundaries about how to effectively make friends.

To be safe is everyone's right and ultimately the aim of any SRE programme should be to enable an individual to possess the skills and understanding for them to be safe. Therefore, those in receipt of an appropriate SRE programme would hopefully become less vulnerable with the potential for more independence. Simultaneously, enabling the individual to develop such skills and understanding should make the wider population less vulnerable because the individuals participating in the programme should possess a greater understanding of the socio-sexual boundaries in place. However, recognising shortfalls and inadequacies in such programmes is important. Therefore, to be able to access the views of those in receipt of an intervention provides more insight into their needs. Gaining such insight is an important part to developing an effective SRE programme for the present

day. With the fast-changing pace of the socio-sexual world, including the complexities of the online world, the views of those living in it are imperative. The aim of Study Two was to access such views from pupils with autistic spectrum condition concerning the SRE programme that they had received within school. As highlighted in the literature review, many previous studies had focussed upon the views of parents and professionals with very little consideration about the views of the pupils. There had been some limited attempts to gain insight from individuals with autistic spectrum condition and/or intellectual disabilities with limited results. In some cases, such studies had focussed more on attitudes relating to sex and sexuality rather than the educational perspective. The majority of studies utilised a range of methods, including 1:1 interviews and surveys. However, the use of focus groups in order to access the interactions between participants that occurs was limited to one study (Hatton & Tector, 2010). The results of that study provided some useful insights into the socio-sexual shortfalls that were present. However, the sample size was limited in number as there were only four individuals involved. Additionally, the information was gained retrospectively as each participant had left the specific school some years previously. Consequently, although the acquired data was useful, it was dependent upon the reliability of participants recollections of the SRE programme.

The benefits of accessing the thoughts and views of pupils with autistic spectrum condition in relation to SRE programmes is particularly useful. It provides insight into the actual needs of individuals with autistic spectrum condition rather than of those implementing such programmes. Such insights enable SRE programmes to be more relevant through the inclusion of such information. In an attempt to gain such feedback from pupils with autistic spectrum condition, the present study was developed and implemented. Study Two utilised the focus group methodology in order to access the knowledge and attitude of participants, as well as benefit from the interactions that can occur amongst participants within a focus group. Throughout Study Two, the focus was upon accessing a greater understanding about the socio-sexual needs of individuals with autistic spectrum condition and what was required from an SRE programme to assist these individuals further. The resulting data, along with the findings of Study One, would guide the development of a future SRE pilot programme.

To perform a focus group requires a number of participants. In the case of Study Two, although participants were found from some of the schools utilised in Study One, the number of participants were limited. It had been hoped that the enthusiasm exhibited by the schools in Study One would have resulted in more groups. In some cases, schools felt that pupils did not meet the criteria to participate in the focus groups, whilst other schools did not respond to the request about the focus group. Within the final five groups, participants were primarily male which is a reflection of the gender imbalance present in people with autistic spectrum condition. The groups took place within the respective schools to reduce any anxiety potentially experienced by participants due to being in an unknown environment. Each focus group lasted up to an hour and was guided by a set of questions compiled for the study. As hoped, the dynamic interaction that can develop within focus groups extended the conversations beyond the original questions. This resulted in participants discussing a number of distinct themes reflecting their views and experiences of SRE teaching within schools. These themes also reflected the frustration displayed by participants about the teaching and lack of preparation for the wider world.

Throughout the focus groups, participants discussed many of the perceived inadequacies of the SRE programmes they had participated in. Knowledge is key to the teaching of any subject, but without the appropriate teaching materials and teaching methodology, passing on such knowledge proves difficult. As has been previously discussed, those individuals with additional processing issues, such as some individuals with autistic spectrum condition, will find the abstract world of socio-sexual life with its ever-changing boundaries difficult to comprehend. Therefore, the effective implementation of the programmes is important, but as the Focus Groups demonstrated, participants felt such programmes were done in a sporadic manner and the quality varied with some participants receiving only limited basic SRE information. Often such implementation was done as a reaction to issues that may have occurred with pupils within the school. Participants also felt that the staff attitude toward the topic added to the lack of teaching. This was often seen by participants as staff treating pupils in a “babyish” way resulting in staff potentially feeling that the pupils did not need to know those specific subjects and so did not teach them. Consequently, the frustration felt by many participants led them to seek information from elsewhere, even though participants recognised that these could be unreliable sources.

5.5.1 Methodological Limitations

Although the focus groups provided a wealth of information regarding the perception and needs of individuals with autistic spectrum condition concerning their thoughts on the sex education they had received, there were some limitations that may have impacted upon the results. Firstly, as highlighted, although there were five groups it was still a small number of participants. This meant that there was no scope for manipulation of the groups in relation to ability levels or mix and so the formation of the groups centred upon the individuals available. This led some groups to be formed of more able individuals resulting in a greater amount of discussion and information compared to other groups formed of less able individuals. As would be expected in any group, there was a mix of personalities present. In some instances, this proved beneficial as it seemed to motivate other quieter members to participate. However, there were situations when one very strong personality was present resulting in them effectively taking over the conversation. When this happened, it led to the moderator having to spend time trying to refocus the conversation. In one instance, this resulted in the school staff making the decision to remove someone due to their disruptive nature. The issue of staff being present occurred in three of the groups and may have impacted upon how comfortable the participants felt about commenting on the sex education programmes. Unfortunately, in all three cases the school had made the decision that a staff member should be there to support the pupils. In addition, there may have been an impact upon two of the groups due to who the moderator was. In these two cases, the moderator had previously been to the schools to do some work around sex education. This meant that many of the pupils already knew the moderator. Consequently, this may have led to these groups feeling more comfortable about talking about the issues. Although this is a positive as it allowed for a rich amount of information, this was in contrast to the other three groups that had to become familiar and comfortable with the moderator in a few minutes.

Finally, as with the data analysis in Study One (See Chapter 4) although the analysis of the data identified a number of themes, the analytical process was performed by an individual researcher. To have strengthened the data, it would have been appropriate to have a second researcher to also

extract themes from the data. This would have enabled triangulation of the data and strengthen the validity of the resulting themes.

Overall the results from Study Two have built upon issues highlighted within the literature review in Chapter Three and Study One. The lack of appropriate SRE programmes due to limited teaching and resources are having a dramatic impact upon the socio-sexual development of individuals with autistic spectrum condition. This is further affected by attitudes in relation to whether such individuals need to be taught such topics or are being partially taught due to staff embarrassment and confidence in the topic. Consequently, those in receipt of the SRE programmes are often left wanting more information and clarity, but in its absence, individuals filled the gaps from less than reliable sources. They are also being left to enter the wider social world without the full understanding of socio-sexual knowledge needed to keep safe. Without the knowledge and practical understanding, individuals with autistic spectrum condition are being placed in vulnerable positions. This vulnerability centres upon the individual potentially being a victim of abuse or exploitation from others due to a lack of understanding surrounding boundaries and others' intentions. Also, there is the potential for this vulnerability to lead to becoming a perpetrator of crime due to a lack of understanding about boundaries, etc. The development of a more appropriate SRE programme, can reduce such vulnerabilities, whilst allowing individuals with autistic spectrum condition to be more independent and develop healthy sexual relationships where appropriate.

Study Two has provided extra insight into how such programmes could look from the aspect of those in receipt of such programmes. This access to such views has previously been limited, but needs to be utilised in the development of a more effective SRE programme for individuals with autistic spectrum condition.

Chapter Six

Study Three - Sexuality and Relationship Education for people with Autistic Spectrum Condition – Pilot Programme Implementation

6.1 Introduction

As the previous studies have highlighted, there are a number of issues surrounding the present school based SRE programme for pupils with Autistic Spectrum Condition. These issues include:

- The implementation of SRE programmes specifically for pupils with autistic spectrum condition,
- Availability of appropriate teaching material and approaches,
- Appropriate content which explores the socio-sexual aspects of life

The results of the previous studies indicated a lack of consistency in how each school developed and implemented such programmes. Often this seemed due to a lack of an SRE programme that was adapted for individuals with Autistic Spectrum Condition especially regarding the socio-sexual aspects of life. Therefore, there is a need for an SRE programme that is designed to effectively meet this need for schools, staff and pupils with an Autistic Spectrum Condition. The following study will explore the development and evaluation of a potential SRE programme that meets the socio-sexual needs via a small scale pilot study.

6.2 The Need for a Pilot Study

Before embarking upon the present study, it is important to understand the concept of a pilot study and its importance. Primarily, a pilot study is a ‘feasibility study intended to guide the planning of a large-scale investigation’ (Thabane et al, 2010; p1). Pilot studies are generally used in two different ways when involved with social science, either they take the form of a feasibility study to test out the approaches to be used for a larger study at some point (Polit et al, 2001), or as a pilot study focuses upon pre-testing a research tool (Baker, 1994). Consequently, a pilot study enables researchers to identify any particular ethical and practical issues that may arise within the main study (Sampson,

2004; Kelly, 2007). This includes any aspects that might fail, potential issues that may occur due to research protocols not being followed, difficulties with methodology or measures (Van Teijlingen & Hundley, 2001). Often the development of a pilot study is based upon a range of approaches to design and evaluation, including interviews and focus groups in order to develop the design, the intervention and the approach to measurement necessarily for a pilot study (Tashakkori & Teddlie, 1998).

6.2.1 Pilot Study Issues

Although pilot studies provide the researcher with a level of guidance for further study, there are problematic issues relating to the usage of pilot studies. Firstly, as previously highlighted, pilot studies are often used to test the feasibility of research, but it is important to recognise that the results of a pilot study are only an indication of the potential results of the later study (Arain et al, 2010). This is due to the frequently small number of participants involved with pilot studies. Such small numbers cannot guarantee a strong statistical underpinning (Van Teijlingen & Hundley, 2001; Thabane et al, 2010). Contamination has also been raised as a difficulty with using pilot studies which occurs when the resulting data becomes part of the main study. Although some researchers (Thabane et al, 2010) feel that it is plausible to include the results, to do so requires the resulting data from the pilot study to have been acquired using the exact protocols used in the main study. An additional contaminate relates to pilot study participants subsequently being involved with the main study but with new data being obtained. This can impact upon the later data as those individuals would have previously experienced the approaches used, thus increasing their knowledge and experiences which will potentially change their response to the interventions used. When considering inclusion of pilot study participants, researchers need to consider such elements against whether there is a need for this group of participants to be included.

The final aspect relating to pilot studies that researchers need to consider relates to the ethics of “conducting a study whose feasibility cannot be guaranteed” (Thabane et al, 2010). It is only ethical when participants are made aware that the pilot study is a ‘dry run’ and may not lead to the implementation of the main study. Although Thabane et al’s (2010) review of research ethics

guidelines, including the Nuremberg Code (1949), the Belmont Report (1979) and Helsinki Declaration (1964), showed a lack of guidelines surrounding this aspect, it is recommended that informing pilot study participants about this is appropriate and fair.

Regardless of the issues that can be involved with pilot studies, their use can greatly benefit the main study. By performing a pilot study, a researcher can learn and make alterations to the main study (Clark-Carter, 2009), which can assist with the focus of a later study.

6.3 Study Methodology

6.3.1 Study Design

Due to the small sample size, a pre- and post-intervention design was planned, with the results of each measure being compared at the different time points. It was not possible to provide a control group, because of the small sample size, and so participants were their own control.

6.3.2 Participants

Participants were sourced from the schools accessed within the previous studies. Consequently, two groups - one Surrey based, and one Kent based, were recruited for the pilot study. Both schools were specialist provision for children and young people with autistic spectrum condition although the Surrey based one catered for all ages from nursery to 19 whilst the Kent based one was for secondary age (11-19). It was unfortunate that more participants could not be recruited, but the recruitment process was impacted upon by commitment issues (e.g. some schools were already participating in other research projects) and/or changes in personnel had occurred since the previous studies (e.g. PSHE co-ordinators left and the role had not been filled by someone else). A total of 21 pupils were recruited, however only 20 participated in the full pilot scheme, and measures were conducted pre and post the intervention. The one participant did not complete the pilot intervention due to them having to be removed from the Post 16 provision prior to the end of the study. This was as a result of a texting incident involving sending explicit material that had occurred between the individual and another pupil within the school. The remaining participants were primarily teenage boys, with only

two teenage girls being involved but both girls were in one group. The overall breakdown of participants was 10% female and 90% male, and there was a mean age of 17.1 years (they were all attending post 16 provision or they were post-16 in their respective schools). In all cases, the participants had a primary diagnosis of Autistic Spectrum Condition and had received some form of sex education from a biological perspective within the school situations, although the amount and quality varied as some had been in mainstream settings prior to entering the post 16 provision.

In addition to the participants, each pilot group included at least one staff member from the school (the Surrey school had one staff member (teaching assistant) and the Kent school had three staff members (the SRE co-ordinator and two teaching assistants)). In both pilot sites, the primary researcher led the pilot programme throughout the nine sessions. The staff were present to provide participants with additional support. The staff members provided assistance should a participant required a break from any of the session, and also supported any participants who required extra input with regard to writing or to clarify what was required for a task. To limit the impact that the staff members may have had on the study results, brief discussions took place between them and the primary researcher prior to and after each session. Also, the primary researcher was present throughout all sessions and so guided what was happening.

6.3.3 Measures

Baseline and post-intervention measures were completed face to face with participants in the respective schools. The measures were used to identify each participant's sexual knowledge and attitudes. All, except the one participant who did not complete the pilot intervention, completed both sets of measures. Consequently, 20 pupils completed all measures and attended the pilot intervention.

The two measures used for pre and post intervention were:

- **Sexual Attitude and Knowledge Scale (SAKS, Heighway & Webster, 2007)**

The Sexual Attitude and Knowledge Scale is a basic test of an individual's sexual attitudes and knowledge. It was developed for use with people with intellectual disabilities with the assessment process lasting about 35-40 minutes. The assessment contains 19 questions accompanied by pictorial scenarios. The assessment is comprised of four subscales:

- Understanding relationships
- Social interactions
- Sexual awareness
- Assertiveness

- **Understanding Consent and Abuse Pictures (UC&A, O'Callaghan & Murphy, 2002)**

UC & A Pictures utilises images from the sex education pack, *Sex and the 3 Rs* (McCarthy & Thompson, 2008). The process involving the completion of the UC&A lasted about 45 minutes and involved participants being shown 10 increasingly intimate scenarios, some consenting and some non-consenting, ranging from consensual hugging in public to rape. In each case, a number of questions were asked, including:

- What is happening in the scenario?
- Describe the feelings of all involved in the scenario
- Asking whether what is happening in the scenario is 'OK' or should be reported.

With both measures, the assessment process was performed by the lead researcher within a private room in each of the respective schools and written notes in addition to the assessment forms were completed to ensure that any relevant expansion in an individual's answer was recorded.

6.3.4 Intervention

As previously highlighted, the aim of the present study was the development and implementation of a pilot SRE programme for individuals with Autistic Spectrum Condition. Prior to commencing the

study, it was necessary to develop such a programme. The development of the programme took into account the feedback both from the previous studies and utilised aspects of the *Keeping Safe* programme (Malovic et al, 2018) developed for teenagers with intellectual disabilities who have displayed harmful sexual behaviour. In addition, there were a number of approaches included some that had been previously developed by this researcher (Mark Brown) in other areas. The overall outline of the programme content was spread over nine sessions to enable thorough exploration of each topic covered, especially the more complex and abstract areas, such as relationships. A synopsis of the sessions is given below (see Appendix H for the full programme).

6.3.4.1 SRE Course Outline

The course utilised as many visual methods as possible, including video vignettes, as people with autistic spectrum condition find this preferable (Thiemann & Goldstein, 2001) and it also provided participants with the opportunity to explore actual scenarios (Haseltine & Miltenberger, 1990; Lumley et al., 1998; Miltenberger et al., 1999). Each of the nine sessions lasted 45 minutes and, as previously described, involved an additional staff member. The general programme of the pilot intervention explored a number of socio-sexual topics.

Course Outline

Session One – Foundation Sex Education

Although it was assumed that all participants would have received some form of Sex and Relationship Education, the interviews and focus groups performed prior to the pilot scheme have highlighted how the level of knowledge acquisition and teaching methods experienced varied depending upon the individual and the support they were provided. Therefore, Session One was aimed at ensuring that all participants possessed the same foundation knowledge in regards to names of body parts, including identifying slang terms for body parts, changes to the body during puberty, types of sexual relationships and sexual acts, and any queries relating to the physical side of sex and relationships were explored. Additionally, as the subsequent sessions explored various socio-sexual aspects (see Appendix H for specific details) with an emphasis upon friendships and relationships as well as making

appropriate choices. To aid with this process, the introduction of “Man at the Crossroads” was made at the end of session one (see Fig. 6.1)

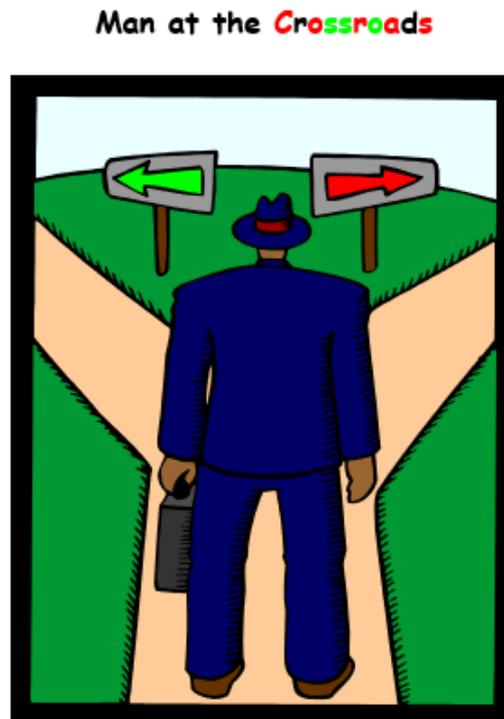


Fig. 6.1 – Man at the Crossroads Visual (with permission to use, The Good Way Model, Ayland, 2006)

This provided a focus upon the decision making process for participants via the green (good) and red (bad) pathways. Each pathway had consequences which were explained throughout the rest of the programme to ensure the thought process was developed within participants by the end of the programme.

Session Two and Three – Relationships

These sessions explored all aspects of relationships including:

- different types of relationships that it is possible to have e.g. family, romantic, professional, etc.
- what type of behaviours are acceptable in different relationships, including sexual relationships?
- good ways of getting to know someone and how to go about developing and maintaining friendships and relationships.

The sessions utilised video vignettes of examples of relationships accessed from the internet to enable participants to talk about what they could see and explore various aspects of building and maintaining relationships. This included various activities such as drawing social circles of their own relationships (See Fig 6.2) (Sinclair et al, 2017) which were then also used in Sessions Six and Seven.

Session Four and Five – Consent and Legal Issues

These sessions centred upon the legal issues associated with socio-sexual side of growing up, including:

- Consent was explored via video vignettes (e.g. clips from ‘This Is Abuse ‘- government campaign (Home Office, 2015)) to highlight how consent can be appropriately and inappropriately gained or coerced from individuals. In regards to consent, the sessions covered what consent means; legal age of consent, verbal and nonverbal consent, impact of issues such as drugs and alcohol.
- The legal aspects were explored in relation to the law and consequences, including arrest, trial and prison, using appropriate visual approaches as well as the use of “story telling” to facilitate participants to progress through the appropriate choices available.

Session Six and Seven – Public/Private

These sessions looked at this topic from the point of view of a person’s body as well as the environment. The former utilised appropriate visual methods to look at where such body parts are, including any non-sexual parts that individual participants classed as their own private parts. In addition, the discussion linked back to the Relationships sessions and the social circle exercise in

regards to what type of touch and interaction can occur with the various people that have been identified as being in a relationship with participants. This also included an addition to the names to include doctor, nurse and police to ensure that although these were strangers, there may be occasions when the former two need to touch private parts or the latter requires to have a conversation as a stranger.

The latter aspect of the environment, also utilised appropriate visual methods including photographs and video, to identify types of location and explore them in detail. Associated with this was the identification of where it is appropriate to participate in various activities, including those of a sexual nature. There was also discussion surrounding public and private in regards to the use of technology, particularly webcam, etc, in various locations.

Session Eight – Online and Technology Issues

This continued the exploration within the previous section. The session utilised “story telling” to explore a number of specific issues regarding the use of technology and the online world. These included the law and consent in relation to the online world, including accessing pornography, how to recognise online abuse and deal with online grooming, improving generally online safety.

Session Nine – Summary

This final session enabled participants to discuss and clarify any issues that had been discussed as well as any topics that may have arisen during the course. In both cases, this session included a general recap of the previous sessions using different scenarios for participants to explore, as well as discussion regarding sexual health and use of contraceptives. This latter aspect was demonstrated to the groups via the use of a false penis and condoms. Following demonstration by the researcher, participants encouraged to practice on the false penis to assess their understanding of the process, which was reinforced by a list of instructions.

In relation to the sessions and materials used, although the approaches utilised were generally consistent between the two pilot sites, on occasions there was a need to adapt some of the material. This need to adapt arose due to differing levels amongst participants, particularly in School 2 where the group were of more mixed abilities in contrast to School 1. One such example was the Social Circle of Relationships (see Fig 6.2).

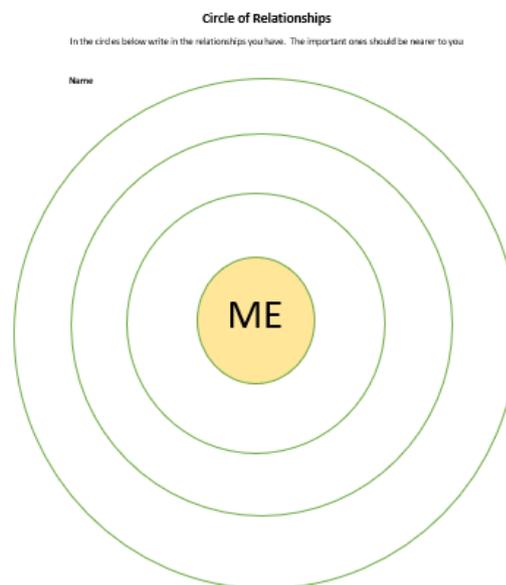


Fig. 6.2 – Social Circle of Relationships Visual Material (SOTSEC-ID, 2017)

This activity involved two elements. Firstly, identifying people in the individual's life and how close they were to the individual. This was then followed by participants considering a list of actions, in relation to the people in their circle including hugging, kissing on the lips, kissing on the cheek and touching private parts. In both schools, the activity was performed using the paper version, however in School 2 many participants found the paper-based approach too abstract. Consequently, it was necessary to adapt the approach so that instead of just focussing purely upon the paper aspect, a more practical and interactive approach was developed in order to enhance the experience and understanding for participants. This involved making a larger version of the Circle of Relationships by drawing chalk circles on the floor and then provide participants with relevant name labels (e.g.

mum, dad, friend, etc). Then for each participant, the group would stand in chosen positions to reflect what was then written down.

6.3.5 Procedure

6.3.5.1 Ethics

As with the previous studies, ethical approval was required for the Pilot Programme, particularly as the process involved individuals with Autistic Spectrum Condition who could be deemed as potentially vulnerable. The ethical approval was similar to Study One and Two insofar as initially this was sought from the Tizard Centre, University of Kent's Ethics Committee (See Appendix N for ethical approval letter). Once again, due to the lack of specific educational ethical committee for local authority schools, the next layer of approval was required from the head teacher of the participating schools for the pilot programme to occur. (See Appendix T and U) Once approval had been gained from either the head teacher or their representative (See Appendix R and S), then groups of students who met the specific criterion were identified to participate in the pilot programme. Only participants with the capacity to consent for themselves were included, and an accessible information sheet with visual supportive pictures, and a consent form (See Appendix P and Q) were used. Both of these were explained to the participants as a group and also one-to-one by the lead researcher.

From the original 21 participants, all consented to participate in the pilot programme, although, as previously highlighted, one participant had to leave the study early. Each participant's parents were also informed about the pilot study and the content being taught. There was no parental resistance to the pilot study. Additionally, due to the pilot study occurring during the Summer Term, there were occasions when some participants had to miss sessions. This was due to other events occurring such as any examinations or transition days for their next placement. In these cases, the participants had the relevant information for the missed session which staff would go through with them. In addition, at the start of each session there would be a review of the previous week's topic.

6.3.5.2 Implementation

Once consent was obtained from participants and both the training room and additional staff members for each group identified, the pilot studies commenced in both schools. As previously stated, the pilot SRE program consisted of 9 weekly sessions with each of the two groups of participants in their respective schools. The materials were developed by the researcher prior to commencement and utilised a range of approaches, including videos, discussion, visual prompts, interactive activities and demonstration. Wherever possible, visual prompts were utilised in an attempt to link the concepts discussed. The pilot studies commenced in April 2017 during the final school term of the year. At the end of each session, staff were encouraged to provide feedback about the sessions as well as being consulted by the researcher concerning any need to adapt the materials for the subsequent sessions. Although no formal method was used to explore the feedback, the discussions provided some insight into how the teaching was progressing.

6.3.6 Analysis

The data obtained from both pre- and post-intervention measures were analysed using SPSS software.

6.4 Results

Due to the small number of test sites and participants, the data obtained were limited. As regards the participants, there were some differences in the ability levels between the two sets. In School 1 participants were of a similar ability level, as well as being generally more able than School 2. Regarding School 2, the review highlighted that the participants were of mixed ability, potentially due to the fact that some of the participants had come from other schools, particularly mainstream schools, into the Post 16 provision.

With regards to the data obtained from the pre and post intervention assessments, although 21 participants completed the pre-intervention assessment as discussed, one participant was unable to complete the pilot intervention and post- intervention measure. Therefore, they were left out of the

final data analysis resulting in 20 participants' data being part of the analysis. The analysis of the 20 participants results showed that the data were somewhat skewed and this, in addition to the small numbers, meant that non-parametric statistics were more suitable. Therefore, a series of Wilcoxon matched pairs signed ranks tests were performed to determine if there were significant pre/post changes in study variables, as shown in Table 6.1.

	N	Minimum	Maximum	Mean	Std. Deviation
Time 1 score on UC & A	20	63.00	102.00	86.3500	11.07047
Time 2 score on UC & A	20	77.00	110.00	96.5500	10.22111
Time 1 SAK relationship score	20	3.00	6.00	5.1000	1.07115
Time 2 SAK relationship score	20	3.00	6.00	5.0750	.86260
Time 1 SAK Social score	20	1.00	3.00	2.7000	.52315
Time 2 SAK Social score	20	1.00	3.00	2.5000	.58490
Time 1 SAK sexual	20	20.00	32.00	25.9750	3.73277
Time 2 SAK sexual	20	23.00	32.00	27.5500	2.98196
Time 1 SAK Assertiveness	20	3.00	10.00	7.7500	2.02290
Time 2 SAK Assertiveness	20	4.00	9.50	7.3250	1.52415
Time 1 Total	20	28.50	50.00	41.5250	6.08163
Time 2 Total	20	32.00	50.00	42.4500	5.33829

Table 6.1 - Results of Wilcoxon matched pairs signed ranks test for pre and post intervention scores

The overall SAKS results indicate that differences between pre-intervention and post-intervention were relatively small and varied. When exploring the results, there was no change in the range for relationships or social scores sub-scales. Regarding sexual and assertiveness sub-scales, both had an increase in the minimum score but only the sexual sub-scale had an increase in the mean score. When analysed separately for each school, School 1 Total SAKS scores did improve significantly ($p > 0.05$) but in contrast School 2 Total SAKS did not improve significantly ($p < 0.05$).

The overall results for the UC & A, on the other hand, showed that there was an increase in all aspects with the minimum score increasing from 63 to 77 and maximum increasing from 102 to 110. When each school was analysed separately, the results indicated that there were significant ($p>0.05$) improvement in the scores for both schools.

6.5 Discussion

The results of the first pilot programme were positive and encouraging for a number of reasons. Firstly, considering the intimate nature of the topic and the discussions that occurred in relation to a range of intimate concepts, none of the participants dropped out of the programme. The only exception was the individual that was unable to complete the programme due to an incident. Such a commitment to the programme came from both participants and their parents/carers/guardians. Regarding the participants, it is important to recognise that on occasions the discussions that occurred within the programme sessions could be uncomfortable for participants. However, regardless of this participant continued to attend and contribute to the sessions even when given the option to physically (leave the sessions) or verbally withdraw if they were finding the session difficult. In addition to the participants not withdrawing from the process, at no point did any of the participants' parents/carers/guardians highlight any issues with what was being discussed within the programme nor did they withdraw any participant from the programme.

Secondly, in contrast to the issues raised within Study One relating to the potential lack of commitment from schools and senior management to provide a comprehensive SRE programme and the comments made at the beginning of this chapter, the two schools that participated in the pilot study were highly committed to the implementation of the programme. Of course, it could be said that both schools were able to access a free resource. However, in both cases to achieve this required a level of commitment as the respective schools were required to give both time and staff to the programme, which they consistently accomplished. Additionally, in both cases, there was an "enthusiasm" from the school and staff to ensure that the students effectively participated in the programme, which was reflected in the staff involvement in the programme sessions and their verbal feedback surrounding the programme content, including discussion relating to any adaptation to the

materials being used and what the staff could do in-between sessions to aid pupils. The issue of commitment was also present within each participating schools' senior management team, unlike some of those schools involved with Study One. Within Study One, a number of those interviewed highlighted a distinct lack of support and commitment from senior management with limited resources being made available for SRE. In contrast the two schools participating in the pilot programme had the support of their senior management throughout the study. This resulted in the pilot programme being a priority and so receiving the appropriate time and resources, including staffing.

When focussing on the intervention results, there are suggestions that the programme and its content has provided some improvement in the sexual attitudes and knowledge in individuals with Autistic Spectrum Condition. There was limited improvement in the sexual knowledge which may be due to the small sample size. Also, this small improvement could have been as a result of previous sex education/ biology lessons that meant that the basic knowledge was already in place. There was a larger improvement in the understanding of consent and abuse, arguably a very crucial part of what pupils need to know.

6.5.1 Methodological Limitations

Though the pilot scheme reaped positive results, there were some limitations to the process. Due to the small number of participants involved it was difficult to control the composition of the pilot groups. When examining the gender mix, it was recognised at the planning stage when ethical approval was requested that due to the gender imbalance present within those diagnosed with Autistic Spectrum Condition there would be more males than females. Although this was unavoidable as both schools reflected the gender imbalance with individuals with Autistic Spectrum Condition, there were concerns whether this imbalance would impact upon the female participants being involved in the process (e.g. would they feel embarrassed to take part in the discussion when outnumbered by males?). However, with the right support from school and research staff the female participants were able to participate, although it is still unknown as to how much of an impact the imbalance may have had on the overall results. The small sample size also meant that there was no

scope to account for ethnicity mix. Although the results of Study One had highlighted that differing ethnicity may have an impact upon an individual's involvement in SRE programmes, it was not possible to explore this aspect in the present study. This was especially true from the cultural and religious belief aspects which could have impacted upon participant involvement. Concerning programme evaluation, although there were measures used these once again primarily only looked at knowledge and attitude acquired as a result of the intervention. These were relatively simple tools and did not consider the overall success of the intervention. Ideally it would have been beneficial to have performed post intervention Focus Groups or interviews with the participants. This would have enabled the researcher to ascertain whether the participants had found the intervention useful as well as further explore how much of the more abstract aspects they were able to utilise appropriately. Unfortunately, as the pilot intervention finished at the end of the school year the majority of the participants left school and went to various post 19 provisions. This made it impractical to perform follow on focus groups or interview but should be considered for any future studies.

Regarding the assessment, there were issues relating to the measures. Although there were some aspects which explored attitude and understanding about socio-sexual situations, the tools primarily focussed upon knowledge. This was similar to those issues discussed within Study One. Although an attempt was made to access measures that assessed behaviour changes, this proved difficult although some aspects of the measures used explore attitude and understanding about socio-sexual situations. Presently these measures do not explore the ability of the individual to transfer knowledge based skills into more practical situations that can cause most difficulties for individuals with Autistic Spectrum Condition. In an attempt to overcome this difficulty, a number of studies have started to explore the development of potential assessment measures that examine the effectiveness of 'abuse prevention programmes' that could potentially be used to evaluate SRE programmes (Bruder & Kroese, 2005; Doughty & Kane, 2010).

Although this proved to be a small-scale study, there were positive results which go toward filling the knowledge gap identified in Study One and Two. The pilot study has also provided insight into the processes used within the study which may need adjusting for any future studies into this area, e.g. assessment tools. The present study acts as a potential springboard for a larger multilocational

study that can utilise the measures being developed in both the Burder & Kroese study and the Doughty & Kane study to more effectively assess the results and practical implementation of the skills and knowledge.

Chapter Seven

Conclusions and Implications for Practice

As the modern world progresses so too does the need for good socio-sexual skills. Such skills are complex and fluid in nature, forever changing depending upon the situation. When faced with social communication difficulties, as are those individuals with autistic spectrum conditions, such skills are a challenge to learn, and this challenge is increased given the present approaches to SRE at schools (Hatton and Tector 2010). Such hindrance can place individuals with autistic spectrum conditions in vulnerable situations. With the government of the day making changes to the SRE curriculum, how are the needs of individuals with autistic spectrum condition being met? The work described in this thesis has explored how the present SRE programmes are utilised for such individuals, and what needs to be improved in order to assist with the development of appropriate socio-sexual skills.

Deficits in socio-sexual knowledge and skills have been demonstrated as key factors in the vulnerability of individuals with intellectual and developmental disabilities and/or autistic spectrum condition (Konstantareas & Lunsy, 1997, McCabe, 1999, Murphy & O'Callaghan, 2004, Tang & Lee, 1999), as well as in the case of such individuals who have displayed inappropriate or harmful sexualised behaviour. It therefore follows that increasing socio-sexual knowledge in individuals with autistic spectrum will lead to decreased vulnerability and risks. In addition, the potential for entering the Criminal Justice System through the display of inappropriate or harmful behaviour is decreased.

The findings of the studies described in this thesis suggests areas in need of change within the present SRE system. Such changes include:

- The attitude of some teaching staff as to whether individuals with autistic spectrum condition need or should be taught SRE.
- Lack of knowledge and skill of those teaching the topic
- Lack of organisational commitment toward such programmes
- The need for flexibility in assisting individuals to develop appropriate socio-sexual knowledge and skills.

Such issues are of serious concern due to the potential implications for individuals with autistic spectrum conditions. In an attempt to alleviate the potential impact of such issues, the thesis has described an attempt to provide an alternative SRE programme aimed at being more accessible and relevant for individuals with autistic spectrum conditions. The purpose of this chapter is to review the findings of the studies performed and their implication in regard to future practice and development of SRE programmes for individuals with autistic spectrum conditions.

7.1 Review of Situation

According to a number of studies (Kijak et al, 2013; Isler et al 2009) the present SRE framework provided within the National Curriculum is seen as being inadequate for pupils with autistic spectrum condition. This inadequacy, which relates to the socio-sexual aspects of sexual development, is a potential contributing factor to the development of someone's capacity to consent (Duke & McGuire, 2009; Murphy & Young, 2005). This, in turn, increases the individual's vulnerability and reduces their sexual empowerment. Accepting, then, that this need for appropriate SRE teaching improves an individual's sexual safety, how might the issues highlighted in the studies be addressed?

The journey to developing the present mainstream SRE curriculum has been gradual with sudden significant boosts in understanding surrounding the subject along the way. In comparison, for individuals with intellectual disabilities and/or autistic spectrum conditions such development has only occurred in the latter part of the 20th century. However, even with such development happening there are still indications that in comparison to their neurotypical counterparts, many individuals with autistic spectrum condition are still receiving minimal SRE (Stokes & Kaur, 2005). Central to the difficulty in the delay regarding SRE and individuals with autistic spectrum condition has been the misconceptions relating to the sexuality and sexual needs of individuals with autistic spectrum condition. The problem with misconceptions has led to individuals with autistic spectrum condition being seen as asexual: possessing no interest in relationships and sexual interactions (Gougeon, 2010; George & Stokes, 2018). Additionally, historically there has been the view that teaching SRE to individuals with intellectual disabilities and/or autistic spectrum condition was not a necessity.

Indeed, such teaching has been seen in the past as being a potential trigger for such individuals to display sexually promiscuous behaviour. Fortunately, as time has progressed, so attitudes have developed and changed somewhat.

Since the 1970s, the understanding of individuals with autistic spectrum conditions and sexuality has greatly improved. The recognition that some individuals with autistic spectrum conditions do want to have a relationship and all that is involved has assisted with the improvement. The findings of the studies reviewed in Chapter 3 and studied in Chapter 4 suggests that in general attitudes have improved. However, as the findings of the thesis indicate, although attitudes have improved, there are still some of the old perceptions present in the implementation of today's SRE programmes. Within schools, the role of SRE co-ordinator is generally taken by either an enthusiastic staff member or member of the school senior management team, either of whom are in the role because they want to be. However, the problem which co-ordinators experience in implementing the SRE curriculum would be alleviated by changes in the attitude of staff and senior management and organisations. The material in this thesis indicates a need to focus upon several difficulties regarding attitude to ensure the appropriate implementation of SRE programmes:

- SRE programmes within any school impact upon other teaching, and for many of the secondary schools (11 years and above) this can impinge upon other topics. Unfortunately, SRE co-ordinators are then faced with the battle to convince teaching staff that SRE is an important subject. However, when ad hoc SRE programmes are implemented, subject teaching staff can be extremely protective of their own subject and so find it to be an annoyance due to the impact that it will have upon their own subject. In many instances, it seemed in Study 1 that this protectiveness originated from the targets being set by government and Ofsted for particular subjects which placed pressure on the teaching staff to ensure that targets were effectively met. With the change in legislation regarding SRE coming in 2020, this targeting and protectiveness may reduce, but there is no guarantee and so SRE co-ordinators may have to continue negotiating the fragile balance between SRE and other subjects to ensure that programmes are delivered.

- Although not as prevalent as in the past, unilateral decisions are being made by teaching staff, according to Study 1 (Chapter 4), regarding whether people with autistic spectrum conditions should be involved in such a curriculum. This is particularly true when pupils are deemed as being unable to engage in an intimate relationship later in life. However, this blinkered view highlights the lack of insight by teaching staff that SRE programmes are all about sex and nothing to do with the importance of wider socio-sexual issues. It is not fully known how such decisions are made, although often this seems to be based upon the individual staff member's perception of the situation and not on any formal assessment. However, is it not the pupil's right to at least understand the concepts of consent and appropriate touch if they are going to receive personal care from others? How would these individuals understand whether they are being abused and have the right to say NO? Unfortunately, this short-sighted view places the individual pupil in a vulnerable position due to a lack of understanding by professionals which could result in issues arising later on requiring emergency ad hoc training to attempt to fill the gap in knowledge. There are occasions when decisions have been made to remove some pupils from certain aspects of SRE, but this was less unilaterally made as it was often based upon discussions about the situation, particularly in cases when there were additional factors relating to the pupil, such as a history of abuse or other difficulties. In these cases, participants of Study 1 said they would attempt to deliver the programme in a more appropriate manner for that specific pupil.
- A lack of staff self-confidence regarding their ability to deliver SRE programmes, as reported by SRE coordinators in Study 1, leads to inconsistency in the programme being delivered. The lack of confidence in delivering the topic was affected by a number of factors. This could be due to the staff member's own personal views and belief systems, including religious and cultural aspects, which meant that talking about such private topics as sex and masturbation was uncomfortable and difficult to implement. Therefore, unless the SRE co-ordinator guides or leads programmes effectively, pupils with autistic spectrum condition will not gain the knowledge and skills required for their socio-sexual needs. Beyond the role of SRE co-ordinator, staff confidence is also affected by the wider school culture, particularly with

regard to how supported they felt in implementation. The government legislation outlines the need for SRE education to take place within schools but does not provide specifics. Therefore, it is reliant upon school senior management teams and school governor boards to develop the policies and procedures outlining what happens within their school. This is important for teaching staff so that they feel protected should there be issues with families, pupils and the teaching, especially if it was felt that the SRE teaching had resulted in misunderstandings by pupils leading to them to display inappropriate socio-sexual behaviour.

Over the years, SRE co-ordinators have also had to work with another sort of barrier, that of the attitude of parents and carers. Historically, there have been issues regarding parental attitude and the impact upon pupils receiving SRE as well as their ongoing development. Although the importance of parents being actively involved in SRE has sometimes been recognised (Pownall et al, 2012), this has not always been the case. Parental involvement is important when teenagers with intellectual disabilities/autistic spectrum condition are frequently reliant upon parents to provide them with appropriate experiences to develop the socio-sexual skills further within a practical situation (Cole & Cole, 1993; Cheng & Udry, 2003; Isler et al, 2009; Pownall, 2010; Szollos & McCabe, 1995). However, historically often such experiences and discussion did not occur due to parental perception about the potential risks that their children are subject to (Ruble & Dalrymple, 1993; Stokes & Kaur, 2005), as well as cultural issues that may occur (Katoda, 1993). However, the findings of this thesis seem to indicate that in contrast to staff attitude, parental attitudes seem to have developed positively over the years. Although no specific data was obtained regarding parents, the fact that parents were not actively withdrawing their children from school based SRE programmes is a good indicator of this positivity. At the time of writing, such attitudinal changes are in contrast to the concerns raised by parents in the past. However, there are areas in the UK where negative views still exist such as recent protests that have occurred in Birmingham from parents of mainstream pupils who are against aspects of the new SRE curriculum being introduced by the government, specifically concerning the teaching of same-sex relationships. One must question why such a change occurred? Is there a recognition by parents that individuals with autistic spectrum condition are more at risk from the wider society and, therefore, need more support and input with their understanding of the socio-sexual world? Whatever the reason, the benefits of exploring this area further may enable a change

in attitude from staff and organisations once there is realisation that the support from parents is available.

The problem with attitudinal issues from staff would be of less concern if not for the detrimental impact it has upon the acquisition of effective socio-sexual knowledge by individuals with intellectual disabilities/autistic spectrum conditions (Nemens & McEwan, 1995; Swango-Wilson, 2011). Such attitude difficulties have not only affected the programme content but also the timing of when SRE programmes were delivered and how long for. Although the legislative changes that are due to occur in 2020 in the UK identify the need for earlier SRE programmes, particularly concerning relationships, this is too late for those that have already been through the educational system. Often such programmes occur later in school life, frequently when pupils with autistic spectrum condition are already in their teenage years. At this point, the discussions regarding earlier aspects of puberty, such as menstruation, erections and wet dreams, are too late for this to be of any major benefit. Additionally, SRE programmes can be hastily developed and taught as a reaction to an incident of inappropriate sexualised behaviour or relationship difficulties that may have occurred within the school environment. Unfortunately, such hastily developed programmes can lack appropriate information and/or be performed too late for any positive impact to occur. Even discussing issues of friendships, relationships and the wider socio-sexual issues can often be done too late for pupils with autistic spectrum condition, resulting in individuals trying to navigate the minefield that is teenage life without the right guidance. The findings of this thesis reinforced this concept with direct feedback from individuals with autistic spectrum conditions (in Study 2, chapter 5), who felt that even in specialist schools such discussions only occurred after relationship issues had occurred. The importance of timing for this topic to be taught is crucial for individuals with autistic spectrum conditions so that they have the knowledge and preparation for the wider socio-sexual life. The resulting gap in knowledge that inadequate and badly timed teaching results in can affect the perceptions of individuals with autistic spectrum conditions regarding sex and relationships, such as believing that sex was 'dirty and nasty' (Brantlinger, 1983; Isler et al, 2009). These gaps and misperceptions frequently result in individuals with autistic spectrum conditions feeling unprepared for the world around them and frustrated by this lack of information that they need. When this occurs these gaps require filling, regardless of whether the information gained is factual or not, and

so individuals with autistic spectrum condition and/or intellectual disabilities will seek to fill the gap regardless of potential misinformation (McCabe, 1999). Whether this comes from the internet, peers, parents, siblings or other sources, unless this information is correct there will be a generation of individuals who are at risk of coercion, potential abuse and/or being labelled as deviant. Misinformation and misunderstanding lead to errors in judgement. Unfortunately, such errors can result in wider consequences, whether an inability to develop appropriate intimate relationships or the display of inappropriate behaviour through a lack of understanding about boundaries and the intentions of others. Ultimately, filling these gaps of knowledge with appropriate, relevant and realistic information is likely to have the potential to keep individuals with autistic spectrum conditions out of the Criminal Justice System.

Beyond the battles in attempting to implement SRE programmes, SRE co-ordinators faced the frustration of a resource and support abyss in order to provide appropriate content for the SRE programmes. The development of such programmes has been relatively successful in the area of individuals with intellectual disabilities. Programmes such as 'Sex and the 3 Rs' (McCarthy & Thompson, 2008) and the EQUALS SRE programme (2010) have been utilised within both educational and care settings for some time. However, with regard to individuals with autistic spectrum condition, such programmes were felt to be inadequate for their needs. These programmes are more geared for individuals with intellectual disabilities rather than individuals with autistic spectrum condition, many of whom may have an IQ in the normal range. For this group, the main difficulty relates more to processing information, particularly the more abstract information. Therefore, adaptation is still required for the programme to have an appropriate impact upon pupils with autistic spectrum conditions, which leads to considerable amount of planning time for teachers and SRE co-ordinators being taken up. Teachers and SRE co-ordinators are faced with the issue of how to pass on information that goes beyond the mechanics and biology of sex. The physical act of sex and all that entails has been central to sex education programmes throughout the years and is often seen as the easier aspect to teach. This seems to be due to the 'black and white' nature of the sexual act. For individuals with autistic spectrum condition, there is very little room for misunderstandings regarding the sexual act. Information and materials are readily available for people to use with very little need to adapt. Often this aspect was taught in a very generic fashion utilising the Biology

curriculum to impart the knowledge and understanding about how the physical aspects of sex would develop. Often the only difficulty for teachers and SRE co-ordinators were the teaching methods used to pass the information on. This depended upon the ability level and processing skills of the pupils they were supporting. Being realistic, with differing learning styles it would be difficult for any teacher to effectively cover every style. However, by keeping teaching simple, concrete, and realistic, e.g. using a model penis to examine use of condoms, rather than the ambiguity of a banana, the more information is retained (Cambridge, 1997).

In contrast, teachers and SRE co-ordinators have more difficulty when faced with the problematic abstract area of socio-sexual skills and knowledge. They are faced with frustration surrounding how to effectively present more abstract information, which has no clear boundaries, and which is an ever changing entity. As the findings presented in this thesis shows, there seems to be no clear 'one size fits all' teaching material or programme, certainly in regards to the socio-sexual skills needed for the modern world. If this had been the case, then the ability for co-ordinators to more easily adapt them would have provided both more time to implement the programme and a greater chance of consistency in how the programme was delivered. This approach may have reduced the incidence of inappropriate socio-sexual behaviour such as described by the study participant SRE co-ordinators. These incidents result in additional work including the involvement of specialist external agencies but would have been avoided if appropriate teaching had been provided.

Consequently, in the absence of any effective developed programme, teaching staff and SRE co-ordinators frequently attempt to develop programmes and materials themselves. These need to have comprehensively incorporated all relevant socio-sexual aspects, as well as being appropriate and relevant to the individuals they support. Unfortunately, as the findings highlighted, this is often unsuccessful due to the range of abilities that can be present within individuals with autistic spectrum conditions. Within the thesis, in Study 3 (chapter 6), although a clear SRE programme had been developed, there was still a need for change and flexibility in how the material was used. Although both pilot sites involved pupils with autistic spectrum conditions, the composition of the pupils in one site included a mix of abilities. This mix centred upon the participants' ability to process information regardless of intellectual ability. It became apparent that alternative approaches are needed to teach

the same information to different groups. This has implications for the teaching staff who somehow have to source further resources as well as access additional planning time, neither of which may be available.

As well as planning and developing materials and methods to effectively support pupils with autistic spectrum condition, it is important that teaching staff and SRE co-ordinators recognise occasions when their ability, knowledge and enthusiasm is simply not enough for the situation. This can be due to lack of knowledge, confidence in delivering the topic, or the need for input from a specialist in the topic. This was particularly true when new issues were raised as being important, such as Female Genital Mutilation, which for many co-ordinators was not an area they knew enough. Whatever the reason, SRE is a complex subject that requires access to external agencies when needed. However, as the findings of the thesis indicates, frequently such support is sparse and potentially costly. As with SRE programmes, external services (particularly statutory ones) are often generic in nature and were not readily available, either because they did not cover the topic, or their own resources were sparse. Where statutory services cannot readily step in, other more costly services have to be accessed. This proves difficult for SRE co-ordinators when schools do not prioritise SRE as a subject to be taught, which is reflected in budgetary constraints, leading to SRE co-ordinators being forced to prioritise based on limited budgets rather than need. To overcome this, SRE co-ordinators attempt to arrange days when relevant professionals would come to school but this can often be affected by difficulties with teaching staff attitudes and organisational priorities. This can result in a logistical nightmare in order for all pupils to receive input whilst SRE co-ordinators tried to appease other teaching staff's attitudes toward the sessions. These implementation difficulties are two-fold. Firstly, services need to re-evaluate their support and approaches toward individuals with autistic spectrum conditions. This does not just centre around schools but also goes beyond this, as the pupils of today will be the adults of tomorrow. These adults with autistic spectrum condition will potentially need further support in this area to remain safe. An absence of follow up proactive support can further place individuals with autistic spectrum condition in vulnerable positions. The second implication relates to schools' prioritisation of SRE, not just in relation to external funding but generally. Of course, as the findings highlighted, this is not just about school but also educational organisations, such as Ofsted. With the forthcoming governmental changes in SRE for 2020, SRE has moved up the

agenda. However, although guidance exists, the methodology and curriculum required are still ambiguous. This ambiguity is particularly problematic with regard to intellectual disabilities and autistic spectrum conditions.

7.2 Recommendations for Practice

The thesis and its subsequent findings have highlighted a number of difficulties in the implementation of SRE programmes for individuals with autistic spectrum conditions which need to be considered and rectified by those involved with pupils who have autistic spectrum conditions. As a consequence, there are a number of recommendations for schools, services and government to consider in spite of the forthcoming legislative changes.

- Attitude changes are central to the processes and includes all levels of staff and management. To achieve such change requires education for all involved to enable them to understand the seriousness of a lack of support for the implementation of SRE programmes for pupils with autistic spectrum conditions. Such education should aim to change the perception as to the priorities that pupils have and need. Not only would such awareness about educational needs need to be aimed at schools but also at the monitoring organisation, Ofsted, who place the measures and targets upon schools and educational establishments.
- External agencies need to review the support and services they are presently providing in regards to SRE within schools, in the community and post education support. As previously mentioned, the pupils of today become adults who will require appropriate support at some point. Also, services have to remember that issues relating to sexual needs, behaviour and sexuality are not limited to just the school environment but do occur beyond these boundaries. As such, services have to become more proactive and flexible in order to go beyond the generic framework and provide support that fits the processing and understanding of those who need it.

- There needs to be a focus on the development of an appropriate SRE programme for individuals with autistic spectrum conditions. The present thesis has demonstrated a potential framework for an SRE programme that can be utilised with pupils who have autistic spectrum condition; however, it has been done on a limited basis with only a small sample. Consequently, further implementation of the programme needs to be completed with a wider range of study sites to enable further evidence concerning the benefits of the approaches utilised to be gathered.

Finally, regardless of the vagueness of the forthcoming government changes to the SRE programme within the UK, it is important for those supporting individuals with autistic spectrum conditions to remember that at the heart of SRE are individuals who need appropriate support and assistance. Utilising aspects of the SRE programme developed for this thesis, the aim of the support regarding a comprehensive SRE development for individuals with autistic spectrum condition is to empower the individual to develop appropriate, and where relevant, intimate relationships. However, it is also about enabling the individual with autistic spectrum condition to be empowered whilst having the knowledge and understanding to make appropriate decisions and head down the 'Green Pathway'. In doing so, the individual is able to keep safe from entering the Criminal Justice System as well as reducing their vulnerability to potential abuse and coercion from others.

References

Ackroyd, S. & Hughes, J. (1992) *Data Collection in Context 2nd Edn* Harlow: Longman

Acocella, I. (2012). The focus groups in social research: advantages and disadvantages. *Quality and Quantity*, 33, 1-12

Allred, P. and David, M. E. 2007 *Get Real About Sex: The Politics and Practice of Sex Education* Open University Press

Allen, D.G, Evans, C., Hider, A., Hawkins, S., Peckett, H., & Morgan, H. (2008) Offending behaviour in adults with Asperger syndrome *journal of Autism and Developmental Disorders* 38, pp 748-758

American Psychiatric Association. TASK FORCE ON DSM-IV., 2000. *Diagnostic and statistical manual of mental disorders: DSM-IV-TR*. American Psychiatric Publishing, Inc.

American Psychiatric Association. TASK FORCE ON DSM-V., 2013. *Diagnostic and statistical manual of mental disorders: DSM-V-TR*. American Psychiatric Publishing, Inc.

Arain, M. Campbell, M. J., Cooper, C. L., & Lancaster, G. A. (2010) What is a pilot or feasibility study? A review of current practice and editorial policy *BMC Medical Research Methodology* 10: 67 pp 1-7

Aras, S., Semin, S., Gunay, T., Orcin, E., and Ozan, S. (2007) Sexual Attitudes and Risk-Taking Behaviors of High School Students in Turkey *Journal of School Health* Vol. 77, 7, 359-366

Armstrong, D., Gosling, A., Weinman, J. and Marteau, T (1997) The Place of Inter-Rater Reliability in Qualitative Research: An Empirical Study *Sociology* Vol 31; Issue 3 pp 597-606

Attwood T (2000) *Asperger's Syndrome: A guide for parents and professionals* Jessica Kingsley Publishers London

Attwood, T., 2006. *The complete guide to Asperger's syndrome*. Jessica Kingsley Pub.

Aunos, M. & Feldman, M.A. (2002) Attitudes towards Sexuality, Sterilization and Parenting Rights of Persons with Intellectual Disabilities *Journal of Applied Research in Intellectual Disabilities* Vol 15, Issue 4, pp 285-296

Australian Health Promoting Schools Association (AHPSA) (1997) National strategy for health promoting schools in Australia: 1998–2001 [Draft] (Canberra, Australian Health Promoting Schools Association for the Public Health Division, Commonwealth Department of Health and Family Services).

Ayland, L. & West, B. (2006) The Good Way model: A strengths-based approach for working with young people, especially those with intellectual difficulties who have sexually abusive behaviour. *Journal of Sexual Aggression* 12(2), 189-201

Baker, T. L. (1994) *Doing Social Research (2nd Edn.)* New York: McGraw-Hill Inc.

Balogh, R., Bretherton, K., Whibley, S., Berney, T., Graham, S., Richold, P., Worsley, C., & Firth, H. (2001) Sexual abuse in children and adolescents with intellectual disability *Journal of Intellectual Disability Research* 45, pp 194-201

Bandura, A. (1994) Social Cognitive Theory and Exercise of Control over HIV Infection *Preventing AIDS* pp25-59

Barbaree, H.E., & Marshall, W.L. (2008) *The Juvenile Sex Offender* The Guilford Press

Baron-Cohen, S., Wheelwright, S., Skinner, R., Martin, J. & Clubley, E. (2001) *The Autism-Spectrum Quotient (AQ): Evidence from Asperger Syndrome/High-Functioning Autism, Males and Females, Scientists and Mathematicians* *Journal of Autism and Developmental Disorders*, Vol. 31, No.1 pp 5-17

Baron-Cohen, S., Hoekstra, R. A., Knickmeyer, R. & Wheelwright, S. (2006) The Autism-Spectrum Quotient (AQ) – Adolescent Version *Journal of Autism and Developmental Disorders* Vol 36, No 3 pp343-350

Baron-Coehn, S., Cassidy, S., Auyeung, B., Allison, C., Achoukhi, M., Robertson, S., Pohl, A., & Lai, M.C. (2014) Attenuation of typical sex differences in 800 adults with autism vs 3,900 controls *Public Library of Science One* 9(7)

Barry-Walsh, J.B., Mullen, P.E (2004) Forensic aspects of Asperger's Syndrome *The Journal of Forensic Psychiatry & Psychology* Vol 15, Issue 1, pp 96-107

Bauminger N & Kasari C (2000) Loneliness and Friendship in High-Functioning Children with Autism *Child Development* 71(2): 447-456

Bay-Cheng, L.Y. (2003) The trouble of teen sex: The construction of adolescent sexuality through school-based sexuality education *Sex Education: sexuality, society and learning* 3:1 pp 61-74

Beardsley, E. H., 1976 Allied against sin: American and British responses to venereal disease in World War I *Medical History* 20(2): 189-202

Beauchamp, T L., Childress, J F., (2001) *Principles of biomedical ethics* Oxford University Press

Becker, M.H., Haefner, D.P., Kasl, S.V., Kirscht, J.P. Maiman, L.A., & Rosenstock, I.M. (1977) Selected Psychosocial Models and Correlates of Individual Health-Related Behaviors *Medical Care* Vol. XV No 5 pp 27-46

Benz, C. and Newman, I. (1998). *Qualitative-Quantitative Research Methodology: Exploring the interactive continuum*, Southern Illinois University Press, Carbondale

Berman, H., Harris, D., Enright, R., Gilpin, M., Cathers, T., Bukovy, G. (1999) Sexuality and the adolescent with a physical disability: understandings and misunderstandings. *Issues in Comprehensive Pediatric Nursing* 22, 183–196

Berument, S. K., Rutter, M., Lord, C., Pickles, A., and Bailey, A. (1999) Autism screening questionnaire: diagnostic validity *The British Journal of Psychiatry* 175, 444-451

Bildt A et al (2005) Social skills in children with intellectual disabilities with and without autism *Journal of Intellectual Disability Research* 49(5) 317-328

Blake, S. and Jolly, J., 2002, 'Evidence and entitlement: teaching about sex and relationships in schools' in Lee, E. and Jenkins, T. (eds) *Teenage Sex: What Should Schools Teach Children?*, London : Hodder and Stoughton.

Blos, P. (1979) *The Adolescent Passage* Guildford, Conn: International Universities Press

Blunn, C., Moore, I., & Alexander, S. (1984) Just as important as learning to boil a kettle. *Community Care* December, 13 pp 22-24

Board of Education (1930) *The health of the schoolchild* (London, His Majesty's Stationery Office).

Board of Education (1943) *Sex education in schools and youth organisations* (London, His Majesty's Stationery Office).

Boehning, A. (2006) Sex Education For Students With Disabilities *Law & Disorder* 1, pp 59-65

Bow, J.N, Quinnell, F.A., Zaroff, M., & Assemany, A. (2002) Assessment of Sexual Abuse Allegations in Child Custody Cases *Professional Psychology: Research and Practice* Vol 33, No 6 pp 566-575.

Boyatzis, R.E. (1998) *Transforming qualitative information: thematic analysis and code development*
Thousand Oaks: Sage

Brantlinger E. (1983) Measuring variation and change in attitudes of residential care staff toward the sexuality of mentally retarded persons. *Mental Retardation* 21, 17–22.

Braun, V. & Clarke, V. (2006) Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3, 77-101.

Brignell, V. 2010 The eugenics movement Britain wants to forget *The New Statesman* Dec 9 2010

Brown, H. 1994 'An Ordinary Sexual Life?': A Review of the Normalisation Principle as it Applies to the Sexual Options of People with Learning Disabilities. *Disability & Society*, 9:2, 123-144

Brown, H., & Stein, J. (1998) Implementing Adult Protection Policies in Kent and East Sussex *Journal of Social Policy* 27, 3, pp 371-396

Brown, H., Stein, J. & Turk, V. 1995 The Sexual Abuse of Adults with Learning Disabilities: Report of a Second Two-Year Incidence Survey *Journal of Applied Research in Intellectual Disabilities* Vol 8, Iss 1, 3-24

Brown, J.D., L'Engle, K.L., Pardun, C.J., Guo, G., Kenneavy, K., & Jackson, C. (2006) Sexy Media Matter: Exposure to Sexual Content in Music, Movies, Television, and Magazines Predicts Black and White Adolescents' Sexual Behavior *Pediatrics* Vol 117 Issue 4 pp 1018-1027

Brown, M. J., (2018) Masturbation. In C. Bates (ed) *Sexuality and Learning Disabilities* (2nd Edition) Pavilion Publishing pages 35-45

Brown R. D. & Pirtle T. 2008 Beliefs of professional and family caregivers about the sexuality of individuals with intellectual disabilities: examining beliefs using a Q-methodology approach. *Sex Education: Sexuality, Society and Learning* 8:1, 59-75

Bruder, C., & Kroese, B. (2005) The efficacy of interventions designed to prevent and protect people with intellectual disabilities from sexual abuse: a review of the literature *The Journal of Adult Protection* Vol. 7 Issue 2. Pp 13-27

Bunston, W. (2000) Working with adolescents and children who have committed sex offences. *Australia and New Zealand Journal of Family Therapy* 21(1), pp 1-7.

Bustard, S. (2003) *Living your life: The sex education and personal development resource for special needs education (revised ed.)* London, UK: The Ann Craft Trust U.K. Brook Publications.

Byers, E.S., Nichols, S., & Voyer, S.D. (2013) Challenging stereotypes: Sexual functioning of single adults with high functioning autism spectrum disorder *Journal of Autism and Developmental Disorders* 43, pp 2617-2627

Cambridge, P. (1997) At whose risk? priorities and conflicts for policy development in HIV and intellectual disability, *Journal of Applied Research in Intellectual Disabilities*, Vol. 10, No. 2, pp. 83-104.

Cambridge, P. (1998) Challenges for safer sex education and HIV prevention in services for people with intellectual disabilities in Britain *Health Promotion International* Vol 13, No 1, pp 67-74

Cambridge, P. & Forester-Jones, R. (2003) Using individualized communication for interviewing people with intellectual disability: A case study of user-centred research. *Journal of Intellectual & Developmental Disability*, 28, pp 5-23

Cambridge, P. & McCarthy, M. (2001) 'User Focus Groups and Best Value in Services for People with Learning Disabilities' *Health and Social Care in the Community* 9: pp 476-89

Campbell, J. L., Quincy, C., Osserman, J. & Pedersen, O. K. (2013) Coding In-depth Semistructured Interviews: Problems of Unitization and Intercoder Reliability and Agreement *Sociological Methods & Research* 43(3), pp 294-320

Carey, M. (1994) Forms of interviewing. *Qualitative Health Research*, 5(4), pp 413-416

Cea, C. D., & Fisher, C. B., (2003) Health Care Decision-Making by Adults With Mental Retardation *Mental Retardation* Vol 41, No 2 pp 78-87

Chakrabarti S, Fombonne E. 2001 Pervasive developmental disorders in preschool children *Journal of the American Medical Association* 285(24):3093-9.

Champion, V.L., & Skinner, C.S, (2008) The Health Belief Model. In: Glanz, K., Rimer, B.K., & Viswanath, K. (Eds) *Health behaviour and health education: Theory, research and practice*. 4th ed. Jossey-Bass; San Francisco

CHANGE 2010 *Talking about sex and relationships: the views of young people with learning disabilities*
CHANGE

Cheng, M.M., Udry, R.: 2002 Sexual behaviors of physically disabled adolescents in the United States. *Journal of Adolescent Health* 31, 48–58

Chia Chen, A., & Thompson, E. 2007 Family-centered care: preventing adolescent risky sexual behaviour: parents matter! *Journal for Specialists in Pediatric Nursing* Vol 12, 2, 119-122

Clark-Carter, D. (2009) *Quantitative Psychological Research: The Complete Student's Companion* Taylor & Francis

Clements, J. & Zarkowska, E. (2000) *Behavioural Concerns and Autistic Spectrum Disorders* Jessica Kingsley Publishers

Cohen Report (1964) *Health education*. Report of a Joint Committee of the Central and Scottish Health Services Councils, Ministry of Health (London, Her Majesty's Stationery Office).

Cole S. S. & Cole T. M. 1993 Sexuality, disability and reproductive issues through the lifespan *Sexuality and Disability* 11, 189-205

Connor, M., & Norman, P. (1996) *Predicting health behaviour: Research and practice with social cognitive models*. Buckingham, UK: Open University Press.

Cook, J. A. 2000 Sexuality and people with psychiatric disabilities *Sexuality and Disability*, Vol. 18, No. 3,

Cooke, P. (2000) *Final report on disabled children and abuse* Nottingham: Ann Craft Trust

Côté-Arsenault, D. & Morrison-Beedy, D. (1999) Practical advice for planning and conducting focus groups. *Nursing Research*, 48(5) pp 280-283

Craft, A. 1994 *Practice Issues in Sexuality and Learning Disabilities* Routledge: London

Craft, A., Davis, J., Williams, M. & Williams, M. (1983) A health and sex education programme: curriculum and resources. In: Craft A., Craft, M. (eds) *Sex education & counselling for mentally handicapped people*. Bath, The Pitman Press: pp 148-185

Creswell, J. W. (2007) *Qualitative inquiry and research design: Choosing among five approaches*. Thousand Oaks, CA: SAGE Publications

Crookes, P. A., & Davies, S., (2004) *Research into Practice – Essential Skills for Reading and Applying Research in Nursing and Health Care. 2nd Edition* Bailliere Tindall, London.

Cunningham, A.B., & Schreibman, L. (2008) Stereotypy in Autism: The Importance of Function *Research in autism spectrum disorders* 2(3) pp 469-479

Currer, C. (1983) *The Mental Health of Pathan Mothers in Bradford: A Case Study of Migrant Asian Women*. Coventry: University of Warwick.

Cuskelly M. & Bryde R. 2004 Attitude towards the sexuality of adults with an intellectual disability: parents, support staff, and a community sample. *Journal of Intellectual and Developmental Disability* 29:3, 255-264

Cutler, J. C. & Arnold, R. C. 1988 Venereal Disease Control by Health Departments in the Past: Lessons for the Present *American Journal of Public Health* Vol. 78, No. 4

Darwin, C. (1871) *The descent of man, and selection in relation to sex* London: Murray

Day K. 1997 Sex offenders with learning disabilities. In S. G. Read (Ed.) *Psychiatry in learning disability* (pp. 278-306) London: W. B. Saunders and Co.

DCSF (Department for Children, Schools and Families) 2008 *Review of Sex and Relationship Education (SRE) in Schools. A report by the External Steering Group.* London: DCSF.

Deacon, J.J (1974) *Tongue Tied: Fifty years of friendship in a subnormality hospital* National Society for Mentally Handicapped Children

Dekker, L. P., Van Der Vegt, E. J. M., & Visser, K. (2015) Improving psychosexual knowledge in adolescents with autism spectrum disorder: Pilot of the tackling teenage training program *Journal of Autism and Developmental Disorders* 45(6), pp 1532-1540

DeLamater, J.D & Hyde, J.S (1998) Essentialism vs. Social Constructionism in the Study of Human Sexuality *The Journal of Sex Research* Vol 35, No 1, pp10-18

DeMyer M. K. 1979 *Parents and Children in Autism* Wiley & Sons

Department for children, schools and families (2008) Government Response to the Report by the Sex and Relationships Education (SRE) Review Steering Group, DCSF

Department for Education 1981 Education Act DOE

Department for Education 1986 Education Act DOE

Department for Education 1993 Education Act DOE

Department for Education 1996 Education Act DOE

Department for Education (2000) *Relationships Education, Relationships and Sex Education (RSE) and Health Education*

Department for Education (2001) *Inclusive schooling: Children with Special Educational Needs* DOE

Department for Education 2014 *Sex and Relationship Education in Schools* DOE

Department for Education (2019) *Relationships Education, Relationships and Sex Education (RSE) and Health Education: Draft statutory guidance for governing bodies, proprietors, head teachers, principals, senior leadership teams and teachers* DOE

Department for Education and Employment 2000 *Sex and Relationship Education Guidance* HMSO.
London

Department of Education and Science (1977) *Health Education in Schools* London HMSO

Department of Health 2001 *Valuing People: a new strategy for learning disability for the 21st Century*
CM5086, HMSO. London

Department of Health 2009 *Valuing People Now: a new three-year strategy for learning disability:
Making it happen for everyone*, HMSO. London

Department of Health (2000) *No Secrets: guidance on protecting vulnerable adults in care* HMSO
London

De Vries, A.L.C., Noens, I.L.J., Cohen-Kettenis, P.T., Van Berckelaer, I.A., & Doreleijers, T.A. (2010)
Autism Spectrum Disorders in Gender Dysphoric Children and Adolescents *Journal of Autism and
Developmental Disorders* Vol 40, Issue 8 pp 930-936

Dewey M. & Everard M. 1974 The near normal autistic adolescent *Journal of Autism and Childhood
Schizophrenia* 4(4), 348-356.

Dey, I (1999) *Grounding Grounded Theory: Guidelines for Qualitative Inquiry* Emerald Group

DHSS (1971) *Better Services for the Mentally Handicapped* Department of Health and Social Security

Dickinson, W.H. (1909) Royal Commission on the Care and Control of the Feeble-Minded *Charity Organisation Review* Vol 25, No 149

Dilorio C, Pluhar E, & Belcher L. 2003 Parent-child communication about sexuality: A review of the literature from 1980-2002. *Journal of HIV/AIDS Prevention & Education for Adolescents & Children*, 5 (3/4):7-28.

Directives for Human Experimentation (1949) *Nuremberg Code: Trials of War Criminals before the Nuremberg Military Tribunals under Control Council Law No. 10*. Vol. 2, pp 181-2 Washington, DC: US Government Printing Office

Ditto, P.H. & Lopez, D.F. (1992) Motivated Skepticism: Use of Differential Decision Criteria for Preferred and Nonpreferred Conclusions *Journal of Personality and Social Psychology* Vol 63, No 4 pp568-584

Dixon, H. (1993) *Chance to choose: sexuality and relationships education for people with learning difficulties*. Cambs, LDA

Dixon, H. & Craft, A. (1992) *Picture yourself* Cambs, LDA.

Doughty, A. H., & Kane, L. M. (2010) Teaching abuse-protection skills to people with intellectual disabilities: A review of the literature *Research in Developmental Disabilities* Vol 31, Issue 2, pp 331-337

Downs, C. & Craft, A. (1999) *Sex in context: strategies for devising guidelines relating to the sexuality of children and adults with profound and multiple impairments* Brighton, Pavilion

Dukes E. & McGuire B. E. 2009 Enhancing capacity to make sexuality-related decisions in people with an intellectual disability *Journal of Intellectual Disability Research* Vol. 53, No. 8, 727-734

Dyer, C. (1987) Sterilisation of mentally handicapped woman *British Medical Journal* Vol 294 pp 1219-1220

Edelson, M.G. (2010) Sexual abuse of children with autism: factors that increase risk and interfere with recognition of abuse. *Disability Studies Quarterly* 30(1), pp 1-17

Edelson, M.G. & Joa, D. (2010) Differences in legal outcomes for male and female children who have been sexually abused *Sexual Abuse* Vol 22, Issue 4 pp 437-42

Edwards, P. Roberts, I., Clarke, M., DiGiuseppi, C., Pratap, S., Wentz, R., and Kwan, I. (2002) Increasing response rates to postal questionnaires: systematic review *British Medical Journal* Vol 324

Ehlers, S., Gillberg, C. and Wing, L., 1999. A screening questionnaire for Asperger syndrome and other high-functioning autism spectrum disorders in school age children. *Journal of Autism and Developmental Disorders*, **29**(2), pp. 129-141.

Engwall, K. (2004) Implication of being diagnosed as a “feeble minded woman”. In K. Kristiansen & R. Traustadóttir (Eds.), *Gender and disability research in the Nordic countries (pp 75-96)*. Lund, Sweden: *Studentlitteratur*

Epstein, D. and Johnson, R. 1998 *Schooling Sexualities*. Buckingham: Open University Press

EQUALS 14-19 EsSENTials (2010) *Sex and Relationships Education: Supplementing Moving On Third Edition Schemes of Work for Students with Learning Difficulties* EQUALS

Erikson, E.H. (1968) *Identity Youth and Crisis* W

European Union Agency for Fundamental Rights (2014) *Violence against women: an EU-wide survey. Main results report*. EUFRA

Faden, R., and Beauchamp, T L. (1986) *A history and theory of informed consent* Oxford University Press.

Falk, I., Guenther, J (2007), 'Generating from qualitative research: case studies from VET in contexts', AXETRA, Crows Nest, paper presented at the 10th Australian Vocational Education and Training Research Conference

Fayette, R. & Bond, C. (2018) A qualitative study of specialist schools' processes of eliciting the views of young people with autism spectrum disorders in planning their transition to adulthood. *British Journal of Special Education* Vol 45, Issue 1, pp 5-25

Feldman, M S., Sköldberg, K., Brown, R N., and Horner, D. (2004) Making Sense of Stories: A Rhetorical Approach to Narrative Analysis *Journal of Public Administration Research and Theory* 14 (2): 147-170

Ferguson, D. (2019) Fear of LGBT-inclusive lessons hark back to 80s, says Peter Tatchell *The Guardian*

Fishbein, M. & Ajzen, I. (1975) *Belief, Attitude, Intention and Behavior: An Introduction to Theory and Research*, Reading, MA: Addison-Wesley

Fishbein, M., Chan, D. K.S>, O'Reilly, K., Schnell, D., Wood, R., Beeker, C., & Cohn, D. (1992) Attitudinal and Normative Factors as Determinants of Gay Men's Intentions to Perform AIDS-Related Sexual Behaviors: A multisite Analysis. *Journal of Applied Social Psychology* Vol 22, Issue 13 pp 999-1011

Fitzherbert T. 2014 Let's talk about sex education and disability *The Guardian*

Fonagy, P. & Target, M. (2002) Early Intervention and the Development of Self-Regulation
Psychoanalytic Inquiry Vol 22 Issue 3, pp 307-335

Fontana, A. & Frey, J.H. (1994) 'Interviewing: the art of science'. In N.K. Denzin & Y.S. Lincoln (eds),
Handbook of Qualitative Research. Thousand Oaks, CA: Sage. Pp.361-76

Foucault, M. (1978) *The history of sexuality. Vol 1: An Introduction* Harmondsworth, UK:Penguin

Frawley, P., Johnson, K., Hillier, L. & Harrison, L. (2003) *Living safer sexual lives: a training and
resource pack for people with learning disabilities and those who support them*. Brighton, Pavilion

Freud, A. (1969) Adolescence as a Developmental Disturbance. In. Lerner, R. M., & Lerner, J. V. (eds)
Theoretical Foundations and Biological Bases of Development in Adolescence (1999) Garland
Publishing Inc.

Freud, S. (1905) *Three Essays on the Theory of Sexuality* Martino Fine Books

Friedrich, W.N., Grambsch, P., Broughton, D., Kuiper, J., & Beilke, R.L. (1991) Normative sexual
behaviour in children. *Pediatrics* 88, pp 456-464

Friedrich, W.N., Fisher, J.L., Broughton, D., Houston, M., & Shafran, C.R. (1998) Normative sexual
behaviour in children: A contemporary sample. *Pediatrics* 101, pp 693-700

Frith, H. & Gleeson, K. (2004) Clothing and Embodiment: Men Managing Body Image and Appearance.
Psychology of Men & Masculinity 5(1), pp 40-48

Gabriels, R.L., & Van Bourgondien, M.E. (2007) Sexuality and autism: Individual family, and community perspectives and interventions. In R.L. Gabriels & D.E Hill (Eds)

Gagnon, J. H., & Simon, W. (1973). *Sexual conduct: The social sources of sexuality*. Chicago: Aldine

Garrison, D. R., Cleveland-Innes, M., Koole, M. and Kappelman, J. (2006) Revisiting methodological issues in transcript analysis: Negotiated coding and reliability *Internet and Higher Education* 9 pp 1-8

Gates, B. (2004) *Learning Disabilities: Towards Inclusion 4th ed.* Churchill Livingstone: London

George, R. & Stokes, M. A. (2018) Sexual orientation in autism spectrum disorder *Autism Research* Vol 11 Issue 1 pp 133-141

Gerhardt, P. (2006) *Sexuality instruction and learners with autism spectrum disorders* Presentation at the Texas State Conference on Autism, Dallas.

Gerhardt, P.F., & Lanier, H. (2011) Addressing the needs of adolescents and adults with autism: A crisis on the horizon *Journal of Contemporary Psychotherapy* 41, 37-45

Germain, R. (2004) An exploratory study using cameras and Talking Mats to access the views of young people with learning disabilities on their out-of-school activities *British Journal of Learning Disabilities* Vol 32, Issue 4, pp 170-174

Ghaziuddin, M., & Greden, J. (1998). Depression in children with autism/pervasive developmental disorders: a case-control family history study. *Journal of Autism and Developmental Disorders*, 28, 111–115.

Gillberg, C., 1998. Asperger syndrome and high-functioning autism. *The British journal of psychiatry*, 172(3), pp. 200-209.

Gillberg, C. & Coleman, M. (1992) *The Biology of the Autistic Syndromes* 2nd Edition, Mac Keith Press

Gilliam, J. (1995) *Gilliam Autism Rating Scale Examiner's Manual*. Austin, TX: Pro-Ed.

Gillon, R (1994) Medical ethics: four principles plus attention to scope. *British Medical Journal* 309: 184-188

Gilmour (2004) Social communication deficits in conduct disorder: a clinical and community survey *Journal of Child Psychology and Psychiatry* 45:5: 967-978

Glanz, K., Rimer, B.K. & Viswanath, K. (eds) (2008) *Health Behavior and Health Education: Theory, Research, and Practice* Jossey-Bass

Glaser, W. and Deane, K., 1999. Normalisation in an abnormal world: A study of prisoners with an intellectual disability. *International Journal of Offender Therapy and Comparative Criminology*, 43(3), pp. 338-356.

Glaser, B. and Strauss, A. (1967). *The Discovery of Grounded Theory: Strategies for Qualitative Research*, Aldine Publishing, Chicago

Glidden, D., Bouman, W.P., Jones, B.A & Arcelus, J. (2016) Gender Dysphoria and Autism Spectrum Disorder: A Systematic Review of the Literature *Sexual Medicine Reviews* Vol 4 Issue 1 pp 3-14

Godley, D., (1996) Tales of Hidden Lives: A Critical Examination of Life History Research with People who have Learning Difficulties. *Disability and Society*, 11, pp 333-348

Goffman, E. (1961) *Asylums: Essays on the Social Situation of Mental Patients and Other Inmates* Routledge

Gougeon N. A. 2009 Sexuality education for students with intellectual disabilities, a critical pedagogical approach: outing the ignored curriculum *Sex Education* Vol. 9, No. 3

Gougeon N. A. (2010) Sexuality and autism: a critical review of selected literature using a social-relational model of disability *American Journal of Sexuality Education* Vol 5, Issue 4 pp 328-361

Graff, H. J., Moyher, R. E., Bair, J., Foster, C., Gorden, M. E., & Clem, J. (2018) Relationships and Sexuality: How is a Young Adult with an Intellectual Disability Supposed to Navigate? *Sexuality and Disability* June, Vol 36, Issue 2, pp 175-183

Green, J., Willis, K., Hughes, E., Small, R., Welch, N., Gibbs, L. & Daly, J. (2007) Generating best evidence from qualitative research: the role of data analysis *Australian and New Zealand Journal of Public Health* Vol 31, No 6 pp 545-550

Greenbaum, T. L., (1988) *The Practical Handbook and Guide to Focus Group Research* Lexington, MA: Lexington. Rev, ed.

Greenspan S. 2002 A sex police for adults with 'mental retardation'? Comment on Spiecker and Steutel *Journal of Moral Education* 31, No. 2

Grieveo, A., McLaren, S. & Lindsay, W. R. 2006 An evaluation of research and training resources for the sex education of people with moderate to severe learning disabilities *British Journal of Learning Disabilities* 35, 30-37

Grisso, T., Grisso, A., & Appelbaum, P.S. (1998) *Assessing competence to consent to treatment: A guide for physicians and other health professionals* Oxford University Press.

Gubrium, J F., and Holstein, J A. (1998) Narrative Practice and the Coherence of Personal Stories *The Sociological Quarterly* Vol. 39, No. 1: 163-187

Guest, G., MacQueen, K. M. & Namey, E. E. (2012) *Applied thematic analysis*. Thousand Oaks, CA: Sage.

Haffner, D.W. (1990) *Towards a new paradigm on adolescent sexual health* SIECUS Report Dec 1992-Jan 1993

Haight S. L. & Faching D. D. 2001 Materials for Teaching Sexuality, Love and Maturity to High School Students with Learning Disabilities *Journal of Learning Disabilities* Vol. 19, No. 6

Hall, L. (1995) *Sex education in Britain 1870 to 1995*, *History Review*, 23, 47–51.

Hall, L. (2000) *Sex, gender and social change in Britain since 1880* London Macmillan

Hall, L. (2004) Birds, bees and general embarrassment: sex education in Britain, from social purity to Section 28, in: R. Aldrich (Ed.) *Private and public. Studies in the history of knowledge and education* (London, Woburn Press).

Hampshire Safeguarding Adults Board (1998) Independent Longcare Inquiry (Buckingham) HSAB

Haracopos, D. & Pedersen, L. 1992 *Sexuality and autism: Danish report*. United Kingdom: Society for the Autistically Handicapped. Retrieved September 15, 2006 from www.Autismuk.com/index9sub.htm.

Hardie, E. & Tilly, L. 2012 *An introduction to supporting people with a learning disability* Learning Matters, London.

Haseltine, B. & Miltenberger, R. G. (1990) Teaching self-protection skills to persons with mental retardation *American Journal of Mental Retardation* 95(2); pp 188-197

Hatton S. & Tector A. 2010 Sexuality and Relationship Education for young people with autistic spectrum disorder: curriculum change and staff support *British Journal of Special Education* Vol. 37 No. 2

Hayashi M., Arakida M., & Ohashi K. 2011 The effectiveness of a sex education program facilitating social skills for people with intellectual disability in Japan *Journal of Intellectual & Developmental Disability* 36(1): 11-19

Hayes, S., 1991. Sex offenders. *Journal of Intellectual and Developmental Disability*, **17**(2), pp. 221-227.

HEBS (2001) Sexual Health Policy Analysis in Selected European Countries. Available online at <http://www.hebs.scot.nhs.uk/services/pubs/pubfulltext.cfm?>

Heer K. 2008 Teenagers, Pregnancy, Learning Disabilities: Wolverhampton City in Context *Journal of Health and Social Care Improvement* June

Heighway, S. M., & Webster, S. K. (2007) *STARS: Skills training for assertiveness, relationships building and sexual awareness* Arlington, Texas: Future Horizons Inc.

Hellemans, H., Colson, K., Verbraeken, C., Vermeiren, R., & Deboutte, D. (2007). Sexual behavior in high-functioning male adolescents and young adults with autism spectrum disorders. *Journal of Autism and Developmental Disorders*, **37**, 260-269.

Henault, I. (2006) *Asperger's syndrome and sexuality: From adolescence through adulthood* Jessica Kingsley Publishers

Henault, L. & Attwood, T. (2002) *The Sexual Profile of Adults with Asperger's Syndrome: The Need for Understanding Support and Sex Education*. Paper presented at the Inaugural World Autism Congress, Melbourne, Australia

Hesse-Biber, S.N. & Leavy, P. (2004) *Approaches to Qualitative Research: A Reader on Theory and Practice* Oxford University Press

Hesse-Biber, S.N. & Leavy, P. (2006) *Emergent Methods in Social Research* SAGE Publications

Hesse-Biber, S. N., & Leavy, P. (2011) *The Practice of Qualitative Research (2nd Edition)* Thousand Oaks CA; Sage

High Court of Justice (2007) *Local Authority X v MM and KM*

Hingsburger, D., Griffiths, D., & Quinsey, V. (1991). Detecting counterfeit deviance: Differentiating sexual deviance from sexual inappropriateness. *The Habilitative Mental Healthcare Newsletter*, 9, 51-54

Hingson, R.W., Strunin, L., Berlin, B.M., & Heeren, T. (1990) Beliefs about AIDS, use of alcohol and drugs, and unprotected sex among Massachusetts adolescents. *American Journal of Public Health* 80, pp 295-299

Holland, T., Clare, I. and Mukhopadhyay, T., 2002. Prevalence of 'criminal offending' by men and women with intellectual disability and the characteristics of 'offenders': implications for research and service development. *Journal of intellectual disability research*, 46, pp. 6-20.

Home Office (1967) *The Sexual Offences Act 1967* London HMSO

Home Office (2003) *The Sexual Offences Act 2003* London HMSO

Home Office 1988 *Local Government Act 1988* London HMSO

Home Office (2004) *Gender Recognition Act 2004* London HMSO

Home Office 2005 *Mental Capacity Act 2005* London HMSO

Home Office 2007 *Mental Health Act 2007* London HMSO

Home Office (2014) *Children and Families Act 2014* London HMSO

Home Office (2015) *This is Abuse campaign; Summary Report* London HMSO

Honor, G. (2004) Sexual behaviour in children: Normal or not? *Journal of Pediatric Health Care* Vol 18, Issue 2, pp 57-64

Horner, S., Rew, L., and Torres, R. (2006) Enhancing Intervention Fidelity: A Means of Strengthening Study Impact. *Journal for specialists in Pediatric Nursing*, 11(2): 80-89

Horner-Johnson, W. & Drum, C.E. (2006) Prevalence of Maltreatment of People with Intellectual Disabilities: A Review of Recently Published Research *Mental Retardation And Developmental Disabilities Research Review* 12: pp 57-69

Hounton, S.H., Carabin, H., & Henderson, N.J. (2005) Towards an understanding of barriers to condom use in rural Benin using the Health Belief Model: A cross sectional survey *BMC Public Health* 5:8

Howlin, P., 2004. *Autism and Asperger syndrome: Preparing for adulthood*. Psychology Press.

Houck, C. (2013) Youth sexting: Balancing media representation and emerging data *The Brown University Child and Adolescent Behavior Letter* 29, pp 1-8

Hubbard, B M., Giese, M L., and Rainey, J (1998) A Replication of Reducing the Risk, a Theory-Based Sexuality Curriculum for Adolescents *Journal of Sexual Health* Vol. 68, No. 6: 243-247

Human Rights Act (1998)

Hydèn, L. C., & Bülow, P. H. (2003) "Who's Talking: Drawing Conclusions from Focus Groups – some Methodological Considerations" *International Journal of Social Research Methodology* Vol 6, No 4, pp 305-321

Irvine, J. M., 2000 Doing It with Words: Discourse and the Sex Education Culture Wars *Critical Inquiry* Vol 27, No 1

Isler A., Tas F., Beytut., & Conk Z. 2009 Sexuality in Adolescents with Intellectual Disabilities *Sexuality & Disability* 27: 27-34

Ito, K. E., Gizlice, Z., Owen-O'Dowd, J., Foust, E., Leone, P. A., & Miller, W. C. 2006 "Parent Opinion of Sexuality Education in a State with Mandated Abstinence Education: Does Policy Match Parental Preference?" *Journal of Adolescent Health*, 39, 634–41.

Jackson, S. 1982 *Childhood and Sexuality* Oxford: Basil Blackwell

James, A. and Prout, A. (eds) 1990 *Constructing and Reconstructing Childhood: Contemporary Issues in the Sociological Study of Childhood* London: Falmer Press

Janssen, A., Huang, H., & Duncan, C. (2016) Gender Variance Among Youth with Autism Spectrum Disorders: A Retrospective Chart Review *Transgender Health* Vol 1.1 pp63-68

Johnson, K. & Traustadottir, R. (2000) *Women with intellectual disabilities: Finding a place in the world* Jessica Kingsley: London

Jones, S. (1985) 'Depth interviewing', in Punch, K.F. (2013) *Introduction to social research: Quantitative and qualitative approaches* SAGE

Jones, R. and Pitt, N. (1999) Health surveys in the workplace: comparison of postal, email and World Wide Web methods *Occupational Medicine* Vol 49, No. 8: 556-558

Kanner, L., 1943. Autistic disturbances of affective contact. *Nervous child*, 2(3), pp. 217-250.

Kaplan, D. (1990) Evaluating and modifying covariance structure models: A review and recommendation *Multivariate Behavioral Research*, 25, pp 137-155

Karellou J. 2007 Parents' attitudes towards the sexuality of people with learning disabilities in Greece *Journal on Developmental Disabilities* 13, No. 3

Kasari, C., Freeman, S F N., Bauminger, N. and Alkin, M C. (1999) Parental Perspectives on Inclusion: Effects of Autism and Down Syndrome *Journal of Autism and Developmental Disorders*. Vol. 29, 4: 297-305

Katoda H. 1993 Parents' and teachers' praxes of and attitudes to the health and sex education of young people with mental handicaps: a study in Stockholm and Tokyo *Journal of Intellectual Disability Research* Vol. 37, No. 2

Kelly, B. (2007) Methodological Issues for Qualitative Research with Learning Disabled Children *Internal Journal of Social Research Methodology* 10(1): pp 21-35

Kempton, W. (1988) *Life Horizons. Physiological and Emotional Aspects of Being Male/Female (Sex Education for People with Special Needs)*. Santa Barbara, CA: James Stanfield

Kennedy, C.H. (1993) *Sexual consent and education assessment* Drexel University, Philadelphia, PA

Khemka, I., & Hickson, L. (2000) Decision-making by Adults with Mental Retardation in Simulated Situations of Abuse *Mental Retardation* Vol 38 No 1 pp 15-26

Kijak R. 2013 The Sexuality of Adults with Intellectual Disability *Sexuality & Disability* 31:109-123

Kinsella, P. (1993) *Supported living: a new paradigm* Manchester: National Development Team

Kirby D. *Emerging Answers: Research Findings on Programs to Reduce Teen Pregnancy*. Washington, DC: National Campaign to Prevent Teen Pregnancy, 2001.

Kirby, D. (2002) The impact of schools and school programs upon adolescent sexual behaviors *The Journal of Sex Research* 39:1 pp 27-33

Kirby, D., Laris, B.A. & Rolleri, L.A. (2007) Sex and HIV Education Programs: Their Impact on Sexual Behaviors of Young People Throughout the World *Journal of Adolescent Health* Vol 40, Issue 3, pp 206-217

Kitzinger, J., & Farquhar, C., (1999) 'The Analytic Potential of "Sensitive Moments" in Focus Group Discussion', in Rosaline S. Barbour and Jenny Kitzinger (eds) *Developing Focus Group Research: Politics, Theory, and Practice*, pp 156-72. Thousand Oaks, CA: Sage.

Knox M., & Hickson F. 2001 The Meanings of Close Friendship: the Views of Four People with Intellectual Disabilities *Journal of Applied Research in Intellectual Disabilities* 14, 276-291

Kohler, P. K, Manhart, L.E., & Lafferty, W.E. 2008 Abstinence-Only and Comprehensive Sex Education and the Initiation of Sexual Activity and Teen Pregnancy *Journal of Adolescent Health*, 42, 4, 344–351

Koller, R. 2000 Sexuality and adolescents with autism *Sexuality & Disability*, 18(2), 125-135

Konstantareas, M .M. & Lunsy, Y. J. (1997) Sociosexual Knowledge, Experience, Attitudes, and Interests of Individuals with Autistic Disorder and Developmental Delay *Journal of Autism and Developmental Disorders* Vol 27, Issue 4 pp 397-413

Krippendorff, K. (1995) On the Reliability of Unitizing Continuous Data *Sociological Methodology* Vol. 25 pp 47-76

Krueger, r. a., (1998) *Moderating Focus groups: Focus Group Kit*. Sage, Thousand Oaks, CA

Ktamer Monat-Haller, R. 1992 *Understanding and Expressing Sexuality: Responsible Choices for Individuals with Developmental Disabilities* Brookes Publishing Co

Kunkel, D., Cope, K.M., & Biely, E. (1999) Sexual messages on television: Comparing findings from three studies *The Journal of Sex Research* Vol 36, Issue 3, pp230-236

Kvale, S. (1996) *Interviews – An introduction to qualitative research interviewing* Thousand Oaks, CA: Sage

Kvale, S. & Brinkmann, S. (2009) *Interviews: Learning the Craft of Qualitative Research Interviewing*. Sage

Lafferty A., McConkey R. & Simpson A. 2012 Reducing the barriers to relationships and sexuality education for persons with intellectual disabilities *Journal of Intellectual Disabilities* 16: 29

Lawrence, P. & Swain, J. 1993 Sex Education Programmes for Students with Severe Learning Difficulties in Further Education and the Problem of Evaluation *Disability, Handicap & Society* Vol 8, No. 4

Lawson, W. (2005) *Sex, Sexuality and the Autism Spectrum* Jessica Kingsley Publishers

Lee, R. M., (2010) *The Secret Life of Focus Groups: Robert Merton and the Diffusion of a Research Method* *The American Sociologist* June, Vol 41, Issue 2, pp 115-141

Leekam, S. R., Libby, S. J., Wing, L., Gould, J., & Taylor, C. (2002) The Diagnostic Interview for Social and Communication Disorders: Algorithms for ICD-10 childhood autism and Wing and Gould autistic spectrum disorder *Journal of Child Psychology and Psychiatry and Allied Disciplines* 43 pp 327-342

Lehman, K. & Leavy, G. (2016) Individuals with gender dysphoria and autism: barriers to good clinical practice *Journal of Psychiatric and Mental Health Nursing* Vol 24, Issue 2-3 pp171-177

Leonard Cheshire Disability (2010) *In Touch: Relationships, Sex Education and Sexual Health* Final Report Leonard Cheshire

Lesko, N. (1996) Denaturalizing adolescence: The politics of contemporary representations *Youth & Society* Vol 28 Issue 2 pp 139-161 Sage

Lesko, N. (1996) Past, present and future conceptions of adolescence *Educational Theory* Vol 46 No 4 pp 453-472

Levy, H. & Packman, W. (2004) Sexual Abuse Prevention for Individuals with Mental Retardation: Considerations for Genetic Counselors *Journal of Genetic Counseling* Vol 13, No 3 pp 189-205

Lewis, J. & Knijin, T. (2002) The Politics of Sex Education Policy in England and Wales and The Netherlands since the 1980s *Journal of Social Policy* Vol 31, Issue 4 pp 669-694

Lewin, K. (1951) *Field theory in social science* New York: Harper Row

Lewis, M. (1998) Thorns on the rose: the history of sexually transmitted diseases in Australia in international perspective (Canberra, Australian Government Publishing).

Lewis L et al (2005) Effects of ICT group work on interactions and social acceptance of a primary pupil with Asperger's Syndrome *British Journal of Educational Technology* 36(5): 739-755

Leyser, Y and Kirk, R. (2004) Evaluating Inclusion: an examination of parent views and factors influencing their perspectives *International Journal of Disability, Development and Education* Vol 51, 4: 271-285

Linell, P., Wilbeck, V., Adelswärd, V. and Bakshi, A. (2001) 'Arguing in Conversation as a Case of Distributed Cognition: Discussing Biotechnology in Focus Groups', in E. Németh (ed.) *Cognition in Language Use: Selected Papers from the 7th International Pragmatics Conference, Vol. 1*, pp. 243-55. Amsterdam: International Pragmatics Association

Lindsay W. R., Bellshaw E., Culross G., Staines C., & Michie A. 1992 Increases in knowledge following a course of sex education for people with intellectual disabilities *Journal of Intellectual Disability Research* 36, 531-539

Lindsay, W., 2002. Research and literature on sex offenders with intellectual and developmental disabilities. *Journal of Intellectual Disability Research*, 46, pp. 74-85.

Litt, D.M & Stock, M.L (2011) Adolescent Alcohol-Related Risk Cognitions: The Roles of Social Norms and Social Networking Sites *Psychology of Addictive Behaviors* 25(4) pp 708-713

Locke, J.L & Bogin, B. (2006) Language and life history: A new perspective on the development and evolution of human language *Behavioral and Brain Sciences* 29, p 259-325

Löfgren-Mårtenson, L. (2012) "I Want to Do it Right!" A Pilot Study of Swedish Sex Education and Young People with Intellectual Disabilities *Sexuality and Disability* 30: 209-225

Lombard M., Snyder-Duch, J. and Bracken C. C. (2002) Content analysis in mass communication: Assessment and reporting of intercoder reliability *Human Communication Research*, 28(4), pp 587-604

Lord, C. & Jones, R.M. (2012) Annual Research Review: Re-thinking the classification of autism spectrum disorders *Journal of Child Psychology and Psychiatry*. May: 53(5): 490-509

LORD, C. , RUTTER, M. & COUTEUR, A. L . (1994) 'Autism Diagnostic Interview–Revised: A Revised Version of the Diagnostic Interview for Caregivers of Individuals with Possible Pervasive Developmental Disorders', *Journal of Autism and Developmental Disorders* 24: 659–85.

LORD, C. , R I S I , S . , LAMBRECHT, L . , COOK, E .H. , LEVENTHAL, B. L . ET AL. 2000 'The Autism Diagnostic Observation Schedule–Generic: A Standard Measure of Social and Communication Deficits Associated with the Spectrum of Autism', *Journal of Autism and Developmental Disorders* 30: 205–23.

Lotan, G. & Ellis, C. (2010) Adults with intellectual and developmental disabilities and participation in decision making: ethical considerations for professional-client practice *Intellectual and Developmental Disabilities* Vol 48, No 2 pp 112-125

Lumley, V. A., & Miltenberger, R. G., (1997) Sexual abuse prevention for persons with mental retardation *American Journal on Mental Retardation*. 101: pp 459-472

Lumley, V. A., Miltenberger, R. G., Long, E. S., Rapp, J. T. & Roberts, J. A. (1998) Evaluation of a sexual abuse prevention program for adults with mental retardation *Journal of Applied Behavior Analysis* 31, pp 91-101

Lunsky Y, Konstantareas MM. (1998). The attitudes of individuals with autism and mental retardation towards sexuality. *Education and Training in Mental Retardation and Developmental Disabilities* 33(1):24-33.

Lunsky Y, Frijters J, Griffiths DM, Watson SL, et al. (2007). Sexual knowledge and attitudes of men with intellectual disability who sexually offend. *Journal of Intellectual and Developmental Disability* 32(2):74-81

Lyden, M. (2007) Assessment of Sexual Consent Capacity *Sexuality and Disability* 25:3, pp 3-20

McCabe M. 1993 Sex education programs for people with mental retardation *Mental Retardation* 31, 377-387

McCabe M. 1994 *Sexuality Knowledge, Experience and Needs Scale for People with Intellectual Disability (SEX KEN-ID)*, 4th edition. School of Psychology, Deakin University: Burwood, Victoria, Australia

McCabe M. 1999 Sexual Knowledge, Experience and Feelings Among People with Disability *Sexuality & Disability* Vol. 17, No. 2

McCarthy, M. (1999) *Sexuality and women with learning disabilities* Jessica Kingsley: London

McCarthy M. & Thompson D (1994) HIV and Safer Sex Work with People with Learning Disabilities. In: A. Craft (ed) *Practice Issues in Sexuality and Learning Disabilities*. London: Routledge.

McCarthy M. & Thompson D (1997) A Prevalence Study of Sexual Abuse of Adults with Intellectual Disabilities Referred for Sex Education *Journal of Applied Research in Intellectual Disabilities* Vol 10 Issue 2 pp 105-124

McCarthy M. & Thompson D 2008 *Sex and the 3Rs: Rights, Risks and Responsibilities 3rd Edition* Pavilion Publishing

McCarthy M. & Thompson D 2010 *Sexuality and Learning Disabilities: A handbook* Pavilion Publishing

McLaren, P. (2007) *Life in schools: An introduction to critical pedagogy in the foundations of education* (5th ed) NY:Pearson

McConkey, R. & Leavey, G. (2013) Irish attitudes to sexual relationships and people with intellectual disability *British Journal of Learning Disabilities* Vol 41, Issue 3, pp 181-188

McGillivray J. A. 1999 Level of Knowledge and Risk of Contracting HIV/AIDS Amongst Young Adults with Mild/Moderate Intellectual Disability *Journal of Applied Research in Intellectual Disabilities* Vol. 12, No. 2

McNichol, J. (1989) Eugenics and the campaign for voluntary sterilization in Britain between the Wars, *Journal of the History of Medicine* 2 pp 147-169

MacKenzie, Donald 1975. "Eugenics in Britain". *Social Studies of Science* 6 (3): 503

Mackenzie, R. & Watts, J. (2013). Sexual health neurodiversity and capacity to consent to sex. *Learning Disability Review*, 18, pp 88-98

Malovic, A., Rossiter, R., & Murphy, G. H. (2018) Keep Safe: the development of a manualised group CBT intervention for adolescents with ID who display harmful sexual behaviours *Journal of Intellectual Disabilities and Offending Behaviour* 9, (1). Pp 49-58

Mandell, D. S., Walrath, C. M., Manteuffel, B., Sgro, G., & Pinto-Martin, J. A. 2005 The prevalence and correlates of abuse among children with autism served in comprehensive community-based mental health settings *Child Abuse & Neglect*, 29, 1359-1372

Manlove, J., Ryan, S., & Franzetta, K. (2004). Contraceptive use and consistency in U.S. teenagers' most recent sexual relationships. *Perspectives on Sexual and Reproductive Health*, 36, 265-275.

Mansell, S., Sobsey, D., & Moskal, R. (1998) Clinical Findings Among Sexually Abused Children With and Without Developmental Disabilities *Mental Retardation* Vol 36, Iss 1 pp 12-22

Marková, I. (2004) 'Langage et communication en psychologie sociale: dialoguer dans les "focus groups"', *Bulletin de Psychologie* 57: pp 231-36

Marková, I., Linell, P., Grossen, M. and Salazar Orvig, A. (2006) *Dialogue in Focus Groups: Exploring Socially Shared Knowledge*. London: Equinox

Marston, C & King, E. (2006) Factors that shape young people's sexual behaviour: a systematic review *The Lancet* 368: pp1581-86

Martin, E. (1989) *The woman in the body* Milton Keynes: Open University Press.

Martinello, E. (2015) Reviewing Risks Factors of Individuals with Intellectual Disabilities as Perpetrators of Sexually Abusive Behaviors *Sexuality and Disability*, Vol. 33, Issue 2, 269-278.

Mason, J. (1996) *Qualitative Researching*. London: Sage

Mazefsky C. A., & Oswald, D. P. 2006 The discriminative ability and diagnostic utility of the ADOS-G, ADI-R, and GARS for children in a clinical setting *Autism* 10; 533

Merrick, M.T., Litrownik, A.J., Everson, M.D., & Cox, C. E. (2008) Beyond Sexual Abuse: The Impact of Other Maltreatment Experiences On Sexualized Behaviors *Child Maltreatment* 13, pp 122-132

Merton, R. K. (1975) *Thematic analysis in science: notes on Holton's concept*. *Science as Culture*, 188(4186), 335-338.

Merton, R. K., Fiske, M., & Kendall, P. L. (1956) *The focused interview*. New York: The Free Press.

Miles, M. B., & Huberman, A. M. (1984) *Qualitative data analysis: A sourcebook for new methods*. Newbury Park, CA: Sage.

Miller, W.L., Yanoshik, M.K., Crabtree, B.F., & Reymond, W.K. 1994. Patients, Family Physicians, and Pain: Vision from Interview and Narratives, *Family Medicine* 26 (3), 179-184

Miller, G., & Dingwall, R. (1997) *Context & Method in Qualitative Research* SAGE Publications

Miltenberger, R. G., Roberts, J. A., Ellington, S., Galensky, T., Rapp, J. T., Long, E. S. & Lumley, V. A. (1999) Training and generalization of sexual abuse prevention skills for women with mental retardation. *Journal of Applied Behavior Analysis* 32, pp 385-388

Ministry of Education (1956) *Health education* London HMSO

Monk, D. 2000 Health and education: conflicting programmes for sex education. In E. Heinze (ed.) *Of Innocence and Autonomy*. Aldershot: Dartmouth Press

Montell, F. (1995) *Focus group interviews: a new feminist method*. Presented at Annu. Meet. Am. Sociol. Assoc., Washington, DC

Moore, S.M & Rosenthal, D.A (2007) *Sexuality in Adolescence* Routledge London

Morgan, D. L. (1996) *Focus Groups as Qualitative Research: Planning and Research Design for Focus Groups* SAGE

Morgan, D. L., & Krueger, R. (1993) When to use focus groups and what. In D. Morgan (Ed.) *Successful focus groups: Advancing the state of the art* (pp. 3-19). Thousand Oaks, CA: Sage

Morris, K.A., & Swann, W.B. (1996) Denial and the AIDS crisis: On wishing away the threat of AIDS. In S. Oskamp & S.C. Thompson (Eds), *The Claremont Symposium on Applied Social Psychology. Understanding and preventing HIV risk behaviour: Safer sex and drug use* Thousand Oaks US: Sage Publications, Inc.

Mort, F. (1987) *Dangerous sexualities. Medico–moral politics in England since 1830* (London, Routledge).

Mowbray, C T., Holter, M C., Teague, G B., and Bybee, D. (2003) Fidelity Criteria: Development, Measurement, and Validation *American Journal of Evaluation* Vol 24, 3: 315-340

Moxon, L. (2016) *Puberty and Growing Up: Children and Young People with ASD Autism Seminar* Presentation 28th April 2016 at The Wave Centre Maryport

Mulhern, T.J. (1975) Survey of reported sexual behaviour and policies characterizing residential facilities for retarded citizens *American Journal of Mental Deficiency* 79, pp 670-673

Munday, J. (2006) Identity in Focus: The Use of Focus Groups to Study the Construction of Collective Identity *Sociology* Vol 40, Issue 1 pp 89-105

Murphy, G.H., (2003) Capacity to consent to sexual relationships in adults with learning disabilities *Journal of Family Planning and Reproductive Health Care* 29, pp 148-49

Murphy, G.H. (2016) Sexual relationships and adults with intellectual disabilities. In A. Carr, C. Linehan, G. O'Reilly, P. Noonan Walsh, J. McEvoy (Eds). *Handbook of Intellectual Disability and Clinical Psychology Practice*. London: Routledge (pp731-759)

Murphy G. H. & O'Callaghan A. 2004 Capacity of adults with intellectual disabilities to consent to sexual relationships *Psychological Medicine* 34, 1347-1357

Murphy, L B. (1993) The Demands of Beneficence *Philosophy & Public Affairs* Vol. 22, 4: 267-292

Murphy, N.A & Elias, E.R. (2006) Sexuality of Children and Adolescents with Developmental Disabilities *Pediatrics* Vol 118, Issue 1. Pp

Murphy N. & Young P. C. 2005 Sexuality in children and adolescents with disability *Developmental Medicine & Child Neurology* Vol. 47, No. 9

Murrie, D.C, Warren, J.I., Kristiansson, M. & Dietz, P.E. (2002) Asperger's Syndrome in Forensic Settings *International Journal of Forensic Mental Health* Vol 1, No 1, pp 59-70

Myers, G. (1998) Displaying opinions: Topics and disagreement in focus groups *Language in Society* Vol 27, Issue 1, pp85-111

Myers, M. (2000) Qualitative research and the generalizability question: Standing firm with Proteus. *The Qualitative Report* 4, 3/4 March 2000

Myles, B.S., & Simpson, R.L. (2002) Asperger Syndrome: An Overview of Characteristics *Focus on Autism and Other Developmental Disabilities* 17, 3, pp132-137

Nakash, R A., Hutton, J L., Jørstad-Stein, E C., Gates, S., and Lamb, S E., (2006) Maximising response to postal questionnaires- A systematic review of randomised trials in health research *BMC Medical Research Methodology* 6:5:

National Autistic Society (2002) *Autism in schools: crisis or challenge?* National Autistic Society

National Autistic Society (2006) *Make School Make Sense* National Autistic Society

National Child Traumatic Stress Network (2009) *Sexual Development and Behavior in Children* NCTSN

National Commission (1979) *The Belmont report: ethical principles and guidelines for the protection of human subjects of research*. Washington DC: US Government Printing Office

National Commission on Excellence in Education (1983) *A Nation at Risk: The Imperative for Educational Reform* National Commission on Excellence in Education

National Information Center for Children and Youth with Disabilities 1992) *Sexuality for children and youth with disabilities* 1(3), pp 1-28

National Institute for Health and Care Excellence 2011 *Autism diagnosis in children and young people: Recognition, referral and diagnosis of children and young people on the autism spectrum* NICE

National Institute for Health and Care Excellence 2012 *Autism spectrum disorder in adults: diagnosis and management* NICE

National Institute for Health and Care Excellence 2017 *Autism spectrum disorder in under 19s: Recognition, referral and diagnosis* NICE

Newens A. J. & McEwan R. 1995 AIDS/HIV awareness training for young people with severe learning difficulties: an evaluation of two school programmes *Journal of Advanced Nursing* 22, 267-275

Noar, S.M., & Zimmerman, R.S. (2005) Health Behavior Theory and cumulative knowledge regarding health behaviors: are we moving in the right direction? *Health Education Research* Vol 20, Issue 3 pp 275-290

O'Callaghan A. & Murphy G. H. 2002 *Capacity to Consent to Sexual Relationships in Adults with Learning Disabilities* Final Report to the Nuffield Foundation

O'Callaghan A. & Murphy G. H. 2003 The impact of abuse on men and women with severe learning disabilities and their families *British Journal of Learning Disabilities* Vol 31, Issue 4 pp 175-180

O'Callaghan A. & Murphy G. H. 2007 Sexual relationships in adults with intellectual disabilities: understanding the law *Journal of Intellectual Disability Research* Vol. 51, No. 3.

Office for National Statistics (2012) *Statistical Bulletin: Conceptions in England and Wales, 2012* Office for National Statistics.

Office for National Statistics (2017) *Statistical Bulletin: Conceptions in England and Wales, 2017* Office for National Statistics.

Office for Standards in Education, Children's Services and Skills (Ofsted) (2013) *Not yet good enough: personal, social, health and economic education in schools* Ofsted

Osler, A. 2005 (ed.) *Teachers, Human Rights and Diversity*. Stoke-on-Trent: Trentham Books

Ousley, O.Y., & Mesibov, G.B. (1991) Sexual attitudes and knowledge of high-functioning adolescents and adults with autism *Journal of Autism and Developmental Disorders* (21(4), pp 471-481

Owen, S. (2001) The practical, methodological and ethical dilemmas of conducting focus groups with vulnerable clients *Journal of Advanced Nursing* 36, pp 652-658

Parahoo, K. (1997) *Nursing Research: Principles, process and issues* Macmillan Press, London

Parchomiuk M. 2012 Specialists and Sexuality of Individuals with Disability *Sexuality & Disability* Vol. 30 Issue 4

Park, D.C & Radford, J.P (1998) From the Case Files: Reconstructing a history of involuntary sterilisation *Disability & Society* Vol 13, Issue 3 pp 317-342

Parritt, S. & O'Callaghan, J. (2000). Splitting the Difference: An exploratory study of therapists' work with sexuality, relationship and disability. *Sexual and Relationship Therapy*. Vol 15. No.2.

Pasterski, V., Gilligan, L. & Curtis, R. (2014) Traits of Autism Spectrum Disorders in Adults with Gender Dysphoria *Archives of Sexual Behavior* 43 pp387-393

Patton, M.Q. (1987). *How to use qualitative methods in evaluation*. Newbury Park: CA, SAGE Publications

Paul, C L., Walsh, R A., and Tzelepis, F. (2005) A monetary incentive increases postal survey responses rates for pharmacists *Journal of Epidemiol Community Health* 59: 1099-1101

Payne, D., Canella-Malone, H.I., Tullis, C.A., & Sabielny, L.M. (2012) The effects of self-directed video prompting with two students with intellectual and developmental disabilities *Journal of Developmental and Physical Disabilities* Vol 24, Issue 6, pp 617

Pilcher, J. 2004 School sex education: policy and practice in England 1870 to 2000 *Sex Education* Vol5, No.2, 153-170

Plowden Report (1967) *Children and their primary schools* (London, Her Majesty's Stationery Office).

Plummer, F.A., Nagelkerke, N.J.D., Moses, S., Ndinya-Achola, J.O., Bwayo, J., & Ngugi, E. (1991) The importance of core groups in the epidemiology and control of HIV-1 infection *AIDS* 5, pp169-176

Polit, D. F., Beck, C. T. & Hungler, B. P. (2001) *Essentials of Nursing Research: Methods, Appraisal and Utilization, 5th Ed.*, Philadelphia: Lippincott Williams & Wilkins

Portway, S. M. & Johnson, B. (2005). Do you know I have Asperger's syndrome? Risks of a non-obvious disability. *Health, Risk & Society, 7(1)*, 73-83.

Pownall, J. D. (2010). *Health knowledge and expected outcomes of risky behaviour: a comparative study of non-disabled adolescents and young people with intellectual and physical disabilities*. Unpublished doctoral dissertation. University of Glasgow, Glasgow, Scotland.

Pownall J. D., Jahoda A. & Hastings R. P. 2012 Sexuality and Sex Education of Adolescents with Intellectual Disability: Mothers' Attitudes, Experiences, and Support Needs *Intellectual and Developmental Disabilities, 50(2)*

Prince-Hughes, D. (2002) *Aquamarine Blue 5: Personal stories of College Students with Autism* Swallow Press Ohio

Public Health England (2018) *Sexually transmitted infections and chlamydia screening in England: 2018*, PHE publications

Punch, M. (1994) *Politics and ethics in qualitative research*, in, Denzin, N. and Lincoln Y (eds) *Handbook of Qualitative Research* London: Sage

Punch, K. F. (2005) *Introduction to Social Research: Quantitative and Qualitative Approaches*. SAGE

Punch, K.F. (2013) *Introduction to social research: Quantitative and qualitative approaches* SAGE

Reilly, P. (1977) *Genetics, Law and Social Policy* Cambridge, Mass: Harvard University Press

Roberts, R.E., Lee, E.S., Hernandez, M., & Solari, A.c. (2004) Symptoms of insomnia among adolescents in the Lower Rio Grande Valley of Texas *Pediatrics* 27:751-60

Rogers, J. (1999) Trying to get it right: undertaking research involving people with learning difficulties. *Disability and Society* 14 (4) pp 421-433

Rohleder P. 2010 Educators' ambivalence and managing anxiety in providing sex education for people with learning disabilities *Psychodynamic Practice* Vol. 16, No. 2

Rohleder, P., Braathen, S.H., Swartz, L., & Eide, A.H. (2009). HIV/AIDS and disability in Southern Africa: A review of relevant literature. *Disability & Rehabilitation*, 31, 51–59.

Rohleder P & Swartz L. 2009 Providing Sex Education to Persons with Learning Disabilities in the Era of HIV/AIDS: Tensions between Discourses of Human Rights and Restriction *Journal of Health Psychology* 14: 601

Rolston, B., Shubotz, D., & Simpson, A. (2005) Sex education in Northern Ireland schools: a critical evaluation. *Sex Education*, 5: pp217-235

Ronis, D.L. (1992) Conditional health threats: Health beliefs, decisions, and behaviors among adults
Health Psychology 11(2), pp 127-134

Roper, N., Logan, W. & Tierney, A. (1990) *The Elements of Nursing*. Churchill Livingstone, Edinburgh

Rosenstock, I.M. (1960) "What Research in Motivation Suggests for Public Health." *American Journal of Public Health*, 50 pp 295-302

Roth, I. 2010 *The Autism Spectrum in the 21st Century: Exploring Psychology, Biology and Practice*
Jessica Kingsley Publishers London

Rothenberg, S. (1999) '*Playing with Self Esteem: The Importance of Social Skills*',

Roulston, K. (2010) *Reflective interviewing: A guide to theory and practice*. SAGE

Roulston, K., deMarrais, K., and Lewis, J.B. (2003) 'Learning to interview in the social sciences',
Qualitative Inquiry, 9(4): 643-668.

Royal College of Nursing (2010) *Mental health nursing of adults with learning disabilities* London:
RCN.

ROYAL COMMISSION ON VENEREAL DISEASES. 1916 *British Journal of Dermatology*, 28: 229–238.

Rubin, H.J. & Rubin, I.S. (1995) *Qualitative Interviewing: The Art of Hearing Data*. 2nd Edition SAGE Publications

Ruble L. A. & Dalrymple M. S. 1993 Social/Sexual Awareness of Persons with Autism: A Parental Perspective *Archives of Sexual Behaviour* Vol. 22, No. 3

Rumsey, J.M., Rapoport, J.L. and Sceery, W.R., 1985. Autistic children as adults: Psychiatric, social, and behavioral outcomes. *Journal of the American Academy of Child Psychiatry*, **24**(4), pp. 465-473.

Russell E & Sofronoff K (2004) *Anxiety and social* worries in children with Asperger Syndrome *Australian and New Zealand Journal of Psychiatry* 39:633-638

Rutter M. 1970 Autistic children: infancy to adulthood. *Seminars in Psychiatry* 2(4):435-50.

Rutter, M., Bailey, A. & Lord, C. (2003) *SCQ: The Social Communication Questionnaire: Manual* Western Psychological Services

Ryan D. & McConkey R. 2000 Staff attitudes to sexuality and people with intellectual disabilities *The Irish Journal of Psychology* 21:1-2, 88-97

Salovey, P., Rothman, A.J., & Rodin, J. (1998) Health behaviour. In D.T. Gilbert, S.T. Fiske, & G. Lindzey (Eds), *The handbook of social psychology* (pp 633-683) New York: McGraw-Hill

Salvador-Carulla L, Reed GM, Vaez-Azizi LM, Cooper SA, Martinez-Leal R, Bertelli M, Adnams C, Cooray S, Deb S, Akoury-Dirani L, Girimaji SC, Katz G, Kwok H, Luckasson R, Simeonsson R, Walsh C, and Munir K, Saxena S. 2011 Intellectual developmental disorders: towards a new name, definition and framework for "mental retardation/intellectual disability" in ICD-11. *World Psychiatry* Oct; 10(3):175-80.

Sampson, H. (2004) Navigating the Waves: the Usefulness of a Pilot in Qualitative Research. *Qualitative Research* 4(3): pp 383-402

Sansosti, F.J. & Powell-Smith, K.A. (2008) Using Computer-Presented Social Stories and Video Models to Increase the Social Communication Skills of Children With High-Functioning Autism Spectrum Disorders *Journal of Positive Behaviour Interventions*. Vol 10, No 3, pp 162-178

Schaafsma D., Stoffelen J. M. T., Kok G. & Curfs L. M. G. 2013 Exploring the Development of Existing Sex Education Programmes for People with Intellectual Disabilities: An Intervention Mapping Approach *Journal of Applied Research in Intellectual Disabilities* 26, 157-166

Schaafsma D., Kok G., Stoffelen J. M. T., Paulien van Doorn & Curfs L. M. G. 2014 Identifying the important factors associated with teaching sex education to people with intellectual disability: A cross-sectional survey among paid care staff *Journal of Intellectual & Developmental Disability* Vol 39 Iss 2 pp157-166

Schofield, M. (1968) *Sexual behaviour of young people* (2nd edn) (Middlesex, Penguin).

Seale, C., Gobo, G., Gubrium, J.F. & Silverman, D. (2007) *Qualitative Research Practice*. SAGE

Seery, M E., Davis, P M., and Johnson, L.J. (2000) Seeing Eye-to-Eye: Are Parents and Professionals in Agreement About the Benefits of Preschool Inclusion? *Remedial and Special Education* Vol. 21, 5: 268-319

Selvin, M. (1984) Changing medical and societal attitudes toward sexually transmitted diseases: a historical overview. In: Holmes, K.K., Mardh, P-A, Sparling, P.F. et al (eds) *Sexually transmitted diseases* New York: McGraw-Hill

Sequeira, H. & Hollins, S. (2003) Clinical effects of sexual abuse on people with learning disability *British Journal of Psychiatry* 182, pp13-19

Servais, L. 2006 Sexual Health Care in Persons with Intellectual Disabilities *Mental Retardation and Developmental Disabilities Research Reviews* 12: 48-56

Servais, L., Leach, R., Jacques, D., & Roussaux, J.P. (2004) Sterilisation of intellectually disabled women *European Psychiatry* 19(7) pp 428-432

Sevlever, M., Roth, M.E., & Gillis, J.M (2013) Sexual Abuse and Offending in Autism Spectrum Disorders *Sexuality and Disability* Vol 31, issue 2 pp 189-200

Shaffer, T.L., & Elkins, J.R. (2005). *Legal interviewing and counselling*. St. Paul, MN:West

Shakespeare, T., Gillespie-Sells, K., & Davies, D. (1996) *The sexual politics of disability, untold desires* London, England: Cassell

Sharp, L.M. and Frankel, J., 1983. Respondent burden: A test of some common assumptions. *Public opinion quarterly*, **47**(1), pp. 36-53.

Sheerin, F. & McKenna, H. (2000) Defining sexuality for holistic nursing practice: an analysis of the concept *All Ireland Journal of Nursing & Midwifery* 1(3), pp 94-99

Sheppard, M.G., & Mayo, J.B. (2013) The social construction of gender and sexuality: Learning from Two Spirit Traditions *The Social Studies* 104(6), pp 259-270

Sherman, D.A.K., Nelson, L.D., & Steele, C.M. (2000) Do messages about health risks threaten the self? Increasing the acceptance of threatening health messages via self-affirmation *Personality and Social Psychology Bulletin* 26(9), pp 1046-1058

Siegel, K., Anderman, S.J., & Schrimshaw, E.W. (2001) Religion and coping with health-related stress *Psychology & Health* Vol 16, Issue 6, pp 631-653

Simpson, A., Lafferty, A. & McConkey, R. (2006) *Out of the Shadows: A Report of the Sexual Health and Wellbeing of People with Learning Disabilities in Northern Ireland* Family Planning Association

Sinason, V. (1994) cited in Craft, A. 1994 *Practice Issues in Sexuality and Learning Disabilities* Routledge: London

Sinclair, N.S, Langdon, P.E, and Murphy, G. H. (2017) *SOTSEC-ID Treatment manual: Cognitive Behavioural Treatment for men with intellectual disabilities who are at risk of offending (2nd ed.)*. Canterbury, UK: SOTSEC-ID

Sinha, S., Curtis, K., Jayakody, A., Viner, E., & Roberts, H. (2005) *Starting sex in east London: protective and risk factors for starting to have sex amongst Black and Minority Ethnic young people in East London*. London: The Teenage Pregnancy Unit.

Smith, Y.L., van Goozen, S.H., Kuiper, A.J., & Cohen-Kettenis, P.T. (2005) Transsexual subtypes: Clinical and theoretical significance. *Psychiatry Research* 137(3), pp 151-160

Smith, J.A., Flowers, P. & Larkin, M. (2009) *Interpretative Phenomenological Analysis: Theory, Method and Research*. SAGE

Sobsey, D. 1994 *Violence and abuse in the lives of persons with disabilities: The end of silent acceptance?* Baltimore: Paul H Brookes Publishing

.

Sofronoff K, Attwood T, Hinton S. 2005 A randomised controlled trial of a CBT intervention for anxiety in children with Asperger syndrome. *Journal of Child Psychology and Psychiatry and allied disciplines* 46(11):1152-60

Somekh, B. & Lewin, C (2006) *Research Methods in the Social Sciences* Thousand Oaks, CA. Sage

South, M. , Williams, B. J. , McMahon, W.M. , Owley, T. , Filipek, P.A. , Shernoff, E . , Corsello, C. , Lainhart, J. E . , Landa, R. & Ozonoff, S . (2002) 'Utility of the Gilliam Autism Rating Scale in Research and Clinical Populations', *Journal of Autism and Related Disorders* 32: 593–9.

Southard, N.Z & Keller, J.L., (2009) The importance of assessing sexuality: a patient perspective *Clinical Journal of Oncology Nursing* Vol 13, No 2 pp 213-217

Speirs, F. 2006 *A Personal Social and Health Education Curriculum for Pupils with Autistic Spectrum Disorder*. Nottingham: The Shepherd School.

Stansfield, A.J., Holland, A.J. & Clare, I.C.H. (2007) The sterilisation of people with intellectual disabilities in England and Wales during the period 1988 to 1999 *Journal of Intellectual Disability Research* Vol 51, Issue 8 pp 569-579

Stehli, A. (ed) (1995) *Dancing in the Rain*. USA: The Georgiana Organization Inc.

Stevens, P. (1996) Focus groups: Collecting aggregate-level data to understand community health phenomena, *Public Health Nursing*, 13, pp170-176

Stokes M. A. & Kaur A. 2005 High-functioning autism and sexuality: A parental perspective *Autism* 9: 266

Stokes, M., Newton, N. and Kaur, A., 2007. Stalking, and social and romantic functioning among adolescents and adults with autism spectrum disorder. *Journal of Autism and Developmental Disorders*, **37**(10), pp. 1969-1986.

Strang, J.F., Kenworthy, L., Dominska, A., Sokoloff, J., Kenealy, L.E., Berl, M., Walsh, K., Menvielle, E., Slesaransky-Poe, G., Kim, K.E., Luong-Tran, C., Meagher, H., & Wallace, G.L. (2014) Increased Gender

Variance in Autism Spectrum Disorders and Attention Deficit Hyperactivity Disorder *Archives of Sexual Behavior* 43(8) pp 1525-1533

Stranger-Hall, K. & Hall, D. (2011) Abstinence-only education and teen pregnancy rates: why we need comprehensive sex education in the U.S, *PLoS One* 6(10)

Sullivan, A., & Caterino, L.C. (2008) Addressing the sexuality and sex education of individuals with autism spectrum disorders *Education and Treatment of Children* 31, pp 381-394

Sullivan F., Bowden K., McKenzie K., & Quayle E. 2013 'Touching people in relationships': a qualitative study of close relationships for people with an intellectual disability *Journal of Clinical Nursing* 22, 3456-3466

Swango-Wilson A. 2008 Caregiver Perceptions and Implications for Sex Education for Individuals with Intellectual and Developmental Disabilities *Sexuality & Disability* 26: 167-174

Swango-Wilson A. 2011 Meaningful Sex Education Programs for Individuals with Intellectual/Developmental Disabilities *Sexuality & Disability* 29: 113-118

Szollos , A.A. , & McCabe , M.P . 1995 The sexuality of people with mild intellectual disability: Perceptions of clients and caregivers. *Australia & New Zealand Journal of Developmental Disabilities*, 20 , 205 – 222 .

Tager-Flusberg, H., Paul, R., & Lord, C. (2005) Language and communication in autism. In F.R Volkmar, R. Paul, A. Klin & D. Cohens (Eds), *Handbook of autism and pervasive developmental disorders* (3rd ed., pp335-364) New Jersey: Wiley

Tang, C. S., & Lee, Y. K., (1999) Knowledge on sexual abuse and self-protection skills: a study on female Chinese adolescents with mild retardation *Child Abuse & Neglect* Vol 23 Issue 3 pp 269-279

Tashakkori, A. & Teddlie, C. (1998) *Mixed Methodology: Combining Qualitative & Quantitative Approaches*, Sage

Taylor, J., Zalewska, A., Gates, J.J., & Millon, G. (2018) An exploration of the lived experiences of non-binary individuals who have presented at a gender identity clinic in the United Kingdom. *International Journal of Transgenderism* Advance online publication
<http://dx.doi.org/10.1080/15532739.2018.1445056>

Thabane, L., Ma, J., Chu, R., Cheng, J., Ismaila, A., Rios, L. P. Robson, R., Thabane, M., Giangregorio, L., & Goldsmith, C. H (2010) A tutorial on pilot studies: the what, why and how *BMC Medical Research Methodology* 10, 1 pp 1-10

Thiemann, K. S. & Goldstein, H. (2001) Social Stories, Written Text Cues, And Video Feedback: Effects on Social Communication of Children With Autism *Journal of Applied Behavior Analysis* 34, No. 4 pp 425-446

Thomas, D. R. (2003) *A general inductive approach for qualitative data analysis* (Internet). Auckland: School of Population Health, University of Auckland.
<http://www.fmhs.auckland.ac.nz/soph/centres/hrmas/aboutus/default.aspx>

Thome, S. (1998) Ethical and Representational Issues in Qualitative Secondary Analysis *Qualitative Health Research* Vol 8, Issue 4 pp 547-555

Thompson, D. and Brown, H. (1997) Men with intellectual disabilities who sexually abuse: A review of the literature. *Journal of Applied Research in Intellectual Disabilities* 10 (2), 140-58.

Thomson, M. (1998) *Reproducing Narrative: Gender, Reproduction and the Law* Aldershot: Dartmouth

Timmers, R. L., DuCharme P. & Jacob G. 1981. "Sexual Knowledge, Attitudes And Behaviors Of Developmentally Disabled Adults Living In A Normalized Apartment Setting." *Sexuality and Disability*, Vol. 4, (No. 1), pp. 27-39.

Trent J. 1994 *Inventing the Feeble Mind: A History of Mental Retardation in the United States* Berkeley, CA: University of California Press

Trivers, R.L. & Campbell, B. (1972) *Sexual selection and the descent of man* Aldinc, Chicago

Tullis, C.A. & Zangrillo, A.N (2013) Sexuality Education for Adolescents and Adults with Autism Spectrum Disorders *Psychology in the Schools* 50: pp 866-875

Turk, J., & Brown, H. (1993) The sexual abuse of adults with learning disabilities: results of a two year incidence survey. *Mental Handicap Research* 6, pp 193-216

United Nations Convention on the Rights of Persons with Disabilities 2006 United Nations

United Nations Demographic Yearbook 2009-2010 United Nations

Valk, G. (2000, July/August). The Dutch model. *UNESCO Courier*, 53(7/8), 19.

Van Bourgondien M. E., Reichle N. C., & Palmer A. 1997 Sexual Behavior in Adults with Autism *Journal of Autism and Developmental Disorders* Vol. 27, No. 2.

Van Teijlingen, E. R., & Hundley, V. (2001) The importance of pilot studies *Social Research Update* Issue 35

Vizard, E., Hickey, N., McCrory, E. (2007) Developmental trajectories associated with juvenile sexually abusive behaviour and emerging severe personality disorder in childhood: 3-year study. *British Journal of Psychiatry* 190, 27-32

Walford, G. (2007) Classification and framing of interviews in ethnographic interviewing, *Ethnography and Education* 2(2), pp 145-157

Warren, C.A.B. (2002) 'Qualitative Interviewing', in J. Gubrium and J Holstein (eds), *Handbook of Interview Research: Context and Method*. Thousand Oaks, CA: Sage

Watson, J.B. (1925) Experimental Studies on the Growth of the Emotions *The Pedagogical Seminary and Journal of Genetic Psychology* Vol 32 Issue 2 pp 328-348

Watson, N., Shakespeare, T., Cunningham-Burley, S., & Barnes, C. (1999) *Life as a disabled child: A qualitative study of young people's experiences and perspectives, final report*. University of Leeds, Disability Research Unit. Leeds, UK: ESRC Research Programme

Webb, E. J., Campbell, D. T., Schwartz, R. D. and Sechrest, L. (1966) *Unobtrusive Measures*. Chicago: Rand McNally

Weeks, J. (1986) *Sexuality* (London, Routledge).

Weiss, R.S. (1994) *Learning from strangers: The art and methods of qualitative Interview studies*. New York: The Free Press

Weinstein, N.D. & Klein, W.M. (1995) Resistance of Personal Risk Perceptions to Debiasing Interventions *Health Psychology* Vol 14, No 2, pp 132-140

Westcott, H.L. & Jones, D.P.H. (1999) Annotation: The Abuse of Disabled Children *Journal of Child Psychology and Psychiatry and Allied Disciplines* 40: pp 497-506

Westminster Education Forum (2018) *Westminster Education Forum Keynote Seminar: Preparing for implementing compulsory relationships and sex education in schools – curriculum content, best practice and teacher training*. Westminster Education Forum

Whitaker, P (2007) Provision for youngsters with autistic spectrum disorders in mainstream schools: what parents say- and what parents want *British Journal of Special Education* Vol 34, 3: 170-178

Whitehouse, M.A., & McCabe, M.P. (1997) Sex Education programs for people with intellectual disability: How effective are they? *Education and Training in Mental Retardation and Developmental Disabilities*, 32(3): pp 229-240

Widmer, E.D., Treas, J., & Newcomb, R. (1998) Attitudes Toward Nonmarital Sex in 24 Countries *Journal of Sex Research* Vol. 35, No 4 pp349-358

Wiedermann, M., W., (2005) The Gendered Nature of Sexual Scripts *The Family Journal: Counselling and Therapy for Couples and Families*, Vol. 13 No. 4 October

Wiggins, L. D., Bakeman, R., Adamson, L. B., & Robins, D. L. (2007) The Utility of the Social Communication Questionnaire in Screening for Autism in Children Referred for Early Intervention *Focus on Autism and Other Developmental Disabilities*

Wilbeck, V., Abrandt Dahlgren, M., & Oberg, G., (2007) Learning in focus groups: An analytical dimension for enhancing focus group research. *Qualitative Research*, 7(2), pp 249-267

Wing, L., 1981. Asperger's syndrome: a clinical account. *Psychological Medicine: A Journal of Research in Psychiatry and the Allied Sciences*,

1979. Severe impairments of social interaction and associated abnormalities in children: epidemiology and classification. *Journal of Autism and Developmental Disorders*, 9(1), pp. 11-29.

Wing, L., Leekam, S. R., Libby, S. J. Gould, J., & Locombe, M. (2002) The Diagnostic Interview for Social and Communication Disorders: Background, inter-rater reliability and clinical use *Journal of Child Psychology and Psychiatry and Allied Disciplines* 43 pp 307-325

Winnicott, D.W. (1992) *Babies and their Mothers* Reading, Mass: Da Capo Press

Wolfensberger, W. 1972. *The principle of Normalization in human services*. Toronto: National Institute on Mental Retardation

Wood Report (1929) *Report of the Mental Deficiency Committee* London: HMSO

Woodard, L.J. 2004 Sexuality and disability *Clinics in Family Practice* Vol 6. No. 4 941-954

Woodbury-Smith, M. R., Robinson, J., Wheelwright, S. & Baron-Cohen, S. (2005) Screening Adults for Asperger Syndrome Using the AQ: A preliminary Study of its Diagnostic Validity in Clinical Practice *Journal of Autism and Developmental Disorders* Vol. 35, No 3. Pp 331-335

Woodbury-Smith, M.R., Clare, I.C.H, Holland, A.J. & Kearns, A. (2006) High functioning autistic spectrum disorders, offending and other law-breaking: findings from a community sample *The Journal of Forensic Psychiatry & Psychology*

World Health Organisation. (1992). *ICD-10 Classifications of Mental and Behavioural Disorder: Clinical Descriptions and Diagnostic Guidelines*. Geneva. World Health Organisation.

World Health Organisation (2002) *Defining sexual health: Report of a technical consultation on sexual health* Geneva World Health Organisation.

World Medical Association (1964) *Declaration of Helsinki* World Health Organisation

Wright, J. (1998) Development and importance of health needs assessment *British Medical Journal* 316(7140) pp 1310-1313

Wright, D. & Digby, A. (1996) *From Idiocy to Mental Deficiency: historical perspectives on people with learning disabilities* Routledge

Wrobel, M. (2003) *Taking Care of Myself: A Hygiene, Puberty and Personal Curriculum for Young People with Autism* Future Horizons

Yacoub E. & Hall I. 2008 The sexual lives of men with mild learning disability: a qualitative study *British Journal of Learning Disabilities* 37, 5-11

Zillman, D. (2000) Influence of unrestrained access to erotica on participants' and young adults' dispositions toward sexuality *Journal of Adolescent Health* 27S pp 42-44

APPENDIX A

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Masters in Autism Survey

re: inappropriate sexualised behaviour

Information relating to incidents of sexually inappropriate or sexually abusive behaviour exhibit in the LAST YEAR

Sexually inappropriate or sexually abusive behaviour refers to any sexually related behaviour for which:

- *the other person was below the age of consent (16 years) or was not consenting or was unable to consent,*
- *the behaviour would be defined as illegal*
- *includes acts such as sexual intercourse, sexual touching, masturbation in public, obscene letters or calls, accessing illegal pornography (eg that related to children)*

This definition excludes sexual behaviours that may be considered strange, but which are not illegal (for example, cross-dressing).

1. What is the school policy relating to an incident of sexually inappropriate or sexually abusive behaviour?

2. Have there been any occurrences of sexually inappropriate behaviour involving any pupils during the last year?

If yes, how many?

3. For each incident, please complete a form on the next page (please copy it as many times as you need).

Incident Description

The following questions relate to the each incident of recorded sexually inappropriate behaviour that occurred in school (please photocopy this sheet so you have the number of sheets you require)

Alleged Perpetrator Profile

1. Age of alleged perpetrator

0-4	5-11	12-16	17+

2. Gender of alleged perpetrator

Male	Female

3. Level of ability – please circle the best description

No language skills

Some comprehension of language, no expressive language

Some comprehension and some expressive language

Fluent expressive language

Any other comments on ability level?

4. Please indicate what their diagnosis is (tick more than one if relevant)

Diagnosis	Please tick all that apply
Aspergers Syndrome	
Autistic Spectrum Disorder	
ADHD	
Dyspraxia	
Down's Syndrome	
Cerebral Palsy	
Oppositional Defiant Disorder	
Obsessive Compulsive Disorder	
Others (please specify)	

5. Please indicate who diagnosed them, if known

Agency	Please tick all that apply
Consultant Paediatrician	
Clinical Psychologist	
Educational Psychologist	
Private Paediatrician	
Private Clinical Psychologist	
Private Educational Psychologist	
Education	
Other (please specify)	

6. Type of sexually inappropriate behaviour exhibited

Please describe what happened and then tick the appropriate boxes below

Type of Sexually Inappropriate Behaviour	Please tick all that apply
Sexual assault, e.g.: <ul style="list-style-type: none"> i) touching of a person's genital areas, including breast, buttocks or penis ii) attempting to forcibly undress a person, iii) attempting to have non-consenting intercourse with a person 	
Exhibitionism (i.e. exposing own sexual body parts)	
Public masturbation	
Propositioning others ie verbal sexual harassment	
Obscene phone calls or letters to others	
Internet access of illegal pornography	
Inappropriate sexual behaviour on facebook or similar site	
Others (please specify)	

7. Was this incident the first of its type for this perpetrator?

If No, how many previous incidents have occurred

1. Location of incident (e.g. school playground / toilets / etc]

Alleged Victims Profile

2. Number of alleged victims in this incident

3. Age of alleged Victim(s)

0-4	5-11	12-16	17+

4. Gender of alleged victim(s)

Male	Female	Total

5. Level of ability of alleged victims – please circle the best description

No language skills

Some comprehension of language, no expressive language

Some comprehension and some expressive language

Fluent expressive language

Any other comments on ability level?

6. Please indicate what their diagnosis is (tick more than one if relevant)

Diagnosis	Please Tick
Aspergers Syndrome	

Autistic Spectrum Disorder	
ADHD	
Dyspraxia	
Down's Syndrome	
Cerebral Palsy	
Oppositional Defiant Disorder	
Obsessive Compulsive Disorder	
Others (please specify)	

7. Please indicate who diagnosed them, if known

Agency	Please Tick
Consultant Paediatrician	
Clinical Psychologist	
Educational Psychologist	
Private Paediatrician	
Private Clinical Psychologist	
Private Educational Psychologist	
Education	
Other (please specify)	

Consequences of the incident

8. Who was informed of the incident?

	Please tick all that apply
Alleged Victim's Family/Carer	
Alleged Perpetrator's Family/Carer	
Police	
Social Services	
LEA	
Other (please specify)	

9. What were the consequences of the incident?

	Please tick all that apply
Exclusion from school (For whom? How long?)	
Multi professional meeting (for whom?): <ul style="list-style-type: none"> - not involving the parents - involving the parents 	
Additional 1:1 support within the school	
Alleged Perpetrator being: <ul style="list-style-type: none"> - formally arrested and taken for questioning - being charged - taken to court (what was the verdict?) 	
Restrictions placed upon the alleged perpetrator <ul style="list-style-type: none"> - please specify 	
Counselling for: <ul style="list-style-type: none"> - alleged victim - alleged perpetrator 	
Other consequences (please specify)	

10. Were services external to school and social services accessed?

If yes, please specify which ones.

11. Was treatment sought for the alleged perpetrator?

If yes, what kind and was it provided?

12. Was treatment sought for the alleged victim?

If yes, what kind and was it provided?

13. How long did the support continue for?

For alleged perpetrator?

For alleged victim?

14. How satisfied were you with the responses of the various authorities and services?

15. Any other comments?

APPENDIX B

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Study One Pre-interview questionnaire

Pre-interview Questionnaire

There is a dearth of information on the development of appropriate sex education programmes for students with autism or Asperger's syndrome. However there are indications that a lack of such methods of early interventions can be a contributing factor in the display of inappropriate sexualised behaviour.

This questionnaire and subsequent interview concerns the sex education programmes being implemented within your school. The aim of collecting this information is to provide information on the approaches used within schools in relation to sex education and pupils with Autism or Asperger's Syndrome. The information gained from the questionnaire and interview will be a guide for further study into supporting pupils with Autism or Asperger's Syndrome who may display inappropriate sexualised behaviour. This study will be planned by Prof Murphy and others at the Tizard Centre, University of Kent.

The information you provide will be treated as absolutely confidential. Your name and your school's name will not be reported in any documents relating to this research. They are simply for our files, so that we can contact you if we have any queries. We DO NOT ask for the student's names so their identities are completely protected.

The pre-interview questionnaire is general information about your school, and the subsequent interview will explore the issue of sex education within your school.

Your name

Your post at the school

School's name and address

School's telephone number

School Background

16. Please provide a brief description of your school

e.g total number of pupils, is the provision attached to a mainstream school

17. Age Breakdown of pupils attending school – please give exact numbers

0-4	5-11	12-16	17+	Total

How many classes are there in each year?

18. Gender Breakdown of pupils attending school – please give exact numbers

Male	Female	Total

19. Please indicate the breakdown of ethnic groups within the school

	Less than 10%	11-20%	21-30%	31-40%	41-50%	51 & above
White (including English/ Welsh/ Scottish/ Irish/ British/ Any other white background)						
Mixed/ Multiple ethnic groups (including White and Black Caribbean/ White and Black African/ White and Asian/ Any other Mixed)						
Asian/ Asian British (including Indian/ Pakistani/ Bangladeshi/						

Chinese/ Any other Asian background)						
Black/ African/ Caribbean/ Black British (including African/ Caribbean/ Any other Black/ African/ Caribbean background)						
Other ethnic group						

If you answered “Other ethnic group”, please provide details and percentages of pupils

20. Please indicate what diagnoses the pupils in your school have (Please tick appropriate boxes)

Diagnosis	Less than 10%	11-20%	21-30%	31-40%	41-50%	51 & above
Asperger’s Syndrome						
Autistic Spectrum Disorder						
ADHD						
Dyspraxia						
Down’s Syndrome						
Cerebral Palsy						
Oppositional Defiant Disorder						
Obsessive Compulsive Disorder						
Others (please specify)						

If you answered “Other” in Question 6, please specify diagnoses and percentage of pupils

21. Do any of the pupils attending school exhibit any of the following forms of general challenging behaviour? (Please tick appropriate boxes)

Type of Behaviour	Less than 10%	11-20%	21-30%	31-40%	41-50%	51 & above
Physical Aggression toward others: <ul style="list-style-type: none"> Such as hitting, biting, kicking, scratching others or throwing objects at people 						
<ul style="list-style-type: none"> Verbal Aggression toward others: <ul style="list-style-type: none"> Such as swearing/insulting others, shouting at others, spitting at others 						
<ul style="list-style-type: none"> Self Injurious Behaviour <ul style="list-style-type: none"> Such as banging own head either with hand or against an object, biting self, kicking self, picking skin, cutting self, using objects to hurt self 						
<ul style="list-style-type: none"> Property Damage <ul style="list-style-type: none"> Such as smashing items, tearing items, breaking items 						
<ul style="list-style-type: none"> Refusal to participate <ul style="list-style-type: none"> Such as trying to leave the class, sitting on the floor and refusing to get up, trying to leave the school premises 						
<ul style="list-style-type: none"> Sexually inappropriate or abusive behaviour <ul style="list-style-type: none"> Please see definition on the next page and please give further details on next page 						
<ul style="list-style-type: none"> Others (please specify) 						

Definition of Sexually inappropriate or sexually abusive behaviour refers to any sexually related behaviour for which:

- *the other person was below the age of consent (16 years) or was not consenting or was unable to consent,*
- *the behaviour would be defined as illegal*
- *includes acts such as sexual intercourse, sexual touching, masturbation in public, obscene letters or calls, accessing illegal pornography (eg that related to children)*

This definition excludes sexual behaviours that may be considered strange, but which are not illegal (for example, cross-dressing).

If you answered “Other”, please specify diagnoses and percentage of pupils

22. What support services are available to pupils, families and staff in relation to challenging behaviour?

Many thanks for completing this survey. The next stage of the study involves a face to face interview with you and one of the researchers to further explore the issue of sex education. We would be most grateful if you could indicate whether you would be willing to take part in the interview at some point before the end of current (2014/15) school year.

APPENDIX C

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Study One Interview Schedule

Sex Education Interview Schedule

INTRODUCTION

My name is Mark Brown, and I am a PhD student at the Tizard Centre, University of Kent, as well as being a special needs advisor working with individuals with special needs and their families. As part of my work, I am frequently involved in supporting individuals with Autistic Spectrum Disorder or Asperger's Syndrome and issues relating to sex and sexuality. It is the subject of sexuality and sex education with this group of individuals which is central to the present study and this interview.

At this point within the study, the aim of this interview is to gain greater insight into the sex education programmes that are being used with individuals with Autistic Spectrum Disorder or Asperger's Syndrome within schools.

Before we start, I would like to highlight that the interview will be taped and later transcribed for analysis. Both the recording and transcription will be stored in a secure area to ensure confidentiality.

If you are still in agreement to participate in this interview, I would like to start by confirming some details about you:

Your Name

Job Title

Name of School

Your link to the sex education programme within the school

What you call your sex education programme (SRE, SRW, PSHE, etc)

Pupils With ASD or Asperger's Syndrome

Please describe how pupils in your school who have a diagnosis of Autistic Spectrum Disorder or Asperger's Syndrome are supported

- Unit, ASD specific school/unit
- Any differentiation of teaching
- Any specific ASD approaches, e.g. PECS, etc

Sex Education School Policy

Please tell me about the general school policy relating to sex education and how it is implemented?

- When does it start, school year
- Age of students for sex education
- What liaison is there with parents
- And do any of the parents ever object, if so what is the procedure
- Are there any grounds for pupil exemption and how is the decision made
- What happens if you are worried about ongoing abuse (between pupils, family and risky behaviour)

Sex Education Programme (Use their title)

Now I would like to look at the specific sex education programme that is used within your school for pupils with ASD or Asperger's Syndrome. How was the programme developed?

- What is it based upon
- who was involved in the planning
- How is the programme co-ordinated, who takes responsibility
- If the school is not ASD specific, how is it different to the wider school programme
- What happens if one individual has difficulties dealing with the topic

Can you tell me about the actual content and implementation of the programme within the school environment, such as methods and materials used?

- How is it taught and who teaches the sex education programme?
- Is there any adaptation to teaching methods, including length of time and methods used
- Length of programme
- Content of curriculum, is there a sex education pack
- How do you evaluate the effectiveness of the programme
- Any topics left out and why
- How is reproduction taught in biology
- How is it coordinated with sex education

Staffing

Now I would like to look at issues relation to the staff training and development. How are the staff prepared for teaching the sex education programme?

- Do you get outside assistance and advice
- Do you know where you can get advice
- Any specific training received.

Is there anything else that you would like to add that we have not covered?

Thank you for taking part in this interview. Would you be prepared to take part in further study in relation to this topic? This would involve potentially a pilot programme for sex education, interviews and/or focus groups with staff/pupils/parents

APPENDIX D

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Study One Information Sheet

What type of sex education programmes are used with students with autism or Asperger's syndrome?

There is a dearth of information on the sex education programmes used with students with autism or Asperger's syndrome.

The online questionnaire concerns details relating to the sex education programme that is used within a range of schools. The aim of collecting this information is to provide basic information on the types of sex education being used within schools, and to inform further research into the area of sex education and sexuality for pupils with autism or Asperger's Syndrome. We are inviting you to take part in this work. Please read this information before you decide.

Why are we asking you?

Your school was chosen because all or some of the students within the school have been diagnosed with either autism or Aspergers syndrome and so meet the research criteria required.

Do you have to take part in the research work?

- No, you do not have to take part in this research work.
- However, if you do agree to participate in the research by completing the questionnaire and interview, you can change your mind at any point.

What do you have to do, if you agree to take part in the research?

As part of the research an online questionnaire and face to face interview have been compiled to examine different aspects of sex education experienced by students within your school.

These questions explore the profile of your school and students as well as the sex education programmes that have been used within the school. These questions need to be answered as honestly as possible in order to provide a clear picture of the present situation. However some questions may be difficult or uncomfortable to answer. In this situation you can decide not to answer the question or discuss it with one of the research team.

The time taken to complete the online questionnaire and face to face interview will depend upon the information provided, but it is hoped that the online questionnaire should take no more than 15 minutes.

What do we want to know?

- We want to know about the profile of the school, including student numbers, gender balance, diagnosis and behavioural difficulties.
- We want to know about the sex education policy and programmes being used within your school.

Is there anything bad about this work?

- You may find some questions and situations explored within the research disturbing and upsetting. In this situation you can discuss the questions with a member of the research team.
- Being part of the research may not help the students directly at present.

In making your decision, you might want to consider potential reasons to take part/not take part.

- By agreeing to participate in the research, you will help other students with autism or Aspergers syndrome because there will be a better understanding as to the needs of these students and provision of support in similar situations.

What if you don't like the way this work is done?

- You can make a complaint to the Tizard Centre at University of Kent.
- We will give you information about how to complain

Will the information you have provided be kept private?

- Yes. All of the results of this work will be kept locked away and only the research worker and supervisor will be able to look at the files.
- If you withdraw, the information you have provided will be destroyed.

What happens at the end?

- We will provide general written feedback about the results of the research.
- If you request, feedback will also be given verbally.
- The research results will be written up by the research team for dissemination to services and professionals. They may be presented at conferences. No school names or addresses will ever be given.

Who are the research workers?

- Professor Glynis Murphy and Mark Brown are the research workers.

Has the work been checked?

- The details of the research have been reviewed by the Tizard Centre (University of Kent) ethics committee to ensure that all aspects are appropriate for the subject being researched.

- To ensure that everyone is provided with comprehensive information about the research prior to completion of the questionnaires, the ethics committee and members of the Tizard Centre have reviewed the level of information provided.

Further information:

- Thank you for reading the information about this work.
- You will be given a copy of the information sheet and consent form.
- If you want any extra information, you can call Professor Glynis Murphy (01227 823960) or Mark Brown (07917454573). Or you can write to Professor Murphy at the Tizard Centre, University of Kent, Canterbury, Kent CT2 7LZ or to Mark Brown at the Tizard Centre, University of Kent, Canterbury, Kent CT2 7LZ.

APPENDIX E

-

Study One Consent Form

School Number:

Participant Identification Number:

CONSENT FORM FOR RESEARCH

Research into the type of sex education programmes used with teenagers with ASD/Aspergers Syndrome.

Name of Researchers: Prof Glynis Murphy, Mark Brown

Please tick \checkmark the 'YES' box if you agree. Put an X if you don't agree.

YES

I have had read and understood the information sheet

I have asked any relevant questions I wanted to

I understand that I do not have to take part in the research

I understand that I can pull out at any time without giving a reason

I understand that all information I provide will be in strict confidence

I understand that the interview will be audiotaped and stored in a secure locations

I agree that members of the research team can and may contact me to clarify information provided by me via the research questionnaire.

I understand that members of the research team will feedback the results of the research to me, in writing, upon completion of the research

I agree to take part in the research

Name: _____

Post held: _____

School Name: _____

Date: _____

Signature: _____

APPENDIX F

-

Study One Ethical Approval Letter

Tizard Ethics Feedback Form

Student Name:	Mark Brown
Supervisor:	Prof Glynis Murphy & Dr Michelle McCarthy
Title:	<i>Sexuality, Autistic Spectrum Disorder and Asperger's Syndrome – Support and Education</i>
<p>Following the recent amendments made to the above proposal the Chair of the Committee has confirmed that the submission has been approved.</p> <p>Signed: J.Ruffels Date: 08.09.14</p> <p>On behalf of Tizard Ethics Committee</p>	
Alterations approved by Supervisor	 Signature Date: 01.10.14
Final approval On behalf of Tizard Ethics Committee	 Signature Date 08.09.14

APPENDIX G

-

Study Two Ethical Approval Letter

Tizard Ethics Feedback Form

Student Name:	Mark Brown	
Supervisor:	Glynis Murphy & Michelle McCarthy	
Title:	<i>“Sexuality, Autistic Spectrum Disorder and Asperger’s Syndrome – support and education”</i>	
<p>The Chair of the Tizard Ethics Committee has considered the amendments made to the above proposal and has given ethical approval.</p> <p>Please ensure that contact details for the Secretary of the Committee are shown on the complaints form.</p>		
Alterations approved by Supervisor	Signature	Date 25.04.16
Final approval On behalf of Tizard Ethics Committee		
	Signature	Date 25.04.16

APPENDIX H

-

Study Two Participant Consent Form



Participant Consent Form

Title of Study: Sexuality, Autistic Spectrum Disorder and Asperger's Syndrome – Support and Education

Name of Researcher: Mark Brown

	You are being invited to take part in Mark's research.	
	If you agree to what is being said then please tick <input type="checkbox"/> the box. If you don't agree then put a X in the box	
	I have read and understood the information sheet	
	I have asked the questions I wanted to	

	<p>I know I do not have to take part in the Focus Groups</p>	
	<p>I know I can leave the Focus Groups without giving any reasons why.</p>	
	<p>I know everything I say will be private unless I tell the researcher that I or someone else is in danger of harm</p>	
	<p>I understand that the Focus Group will be filmed and taped, and these will be put in a secure location</p>	

	<p>I know the researchers will tell me about the results of the Focus Groups when they are all finished</p>	
	<p>I agree to take part in the Focus Group</p>	

Name:

Date

APPENDIX I

-

Study Two Participant Information Sheet



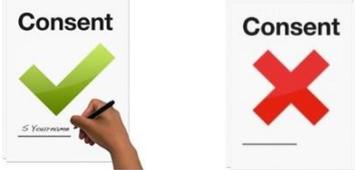
Participant Information Sheet

Title of Study: Sexuality, Autistic Spectrum Disorder and Asperger's Syndrome – Support and Education

Name of Researcher: Mark Brown

	<p>You are being invited to take part in Mark's research.</p>
	<p>Mark is studying for his doctorate at the University of Kent.</p> <p>Mark's research is finding out about the experiences of adolescents with Autism or Asperger's Syndrome in relation to their sex education at school.</p>
	<p>Mark wants to do Focus Groups which are group discussions about the subject. He wonders if you would like to take part in a Focus Group in your school?</p>
	<p>In the Focus Group, there will be other pupils from your school all talking about sex education.</p> <p>The focus group will be filmed.</p>

	<p>What will the Focus Groups talk about?</p> <p>Whether you have had sex education lessons and what did you do in them</p> <p>What you understood in the lessons.</p> <p>How were the lesson taught</p> <p>Is there anything you wish you had learnt about</p>
	<p>There are no right and wrong answers.</p>
	<p>What happens if I say “yes” to doing the Focus Group?</p> <p>It means that a group of pupils from your school will meet with Mark in a quiet room at school.</p> <p>No teachers or school staff can listen to your answers there.</p> <p>Mark will support you in taking part in the Focus Group</p>
	<p>What if I have difficult feelings when taking part in the Focus Group?</p> <p>If you feel upset, angry or uncomfortable you can talk to Mark or you can talk to a member of school staff.</p>

	<p>Who might see my answers?</p> <p>Your answers will be private and only known to Mark.</p> <p>But if your answers show you or someone else may be hurt, we might have to talk to someone, like your class teacher.</p> <p>We will tell you if we need to do this.</p>
	<p>Will other people know who I am?</p> <p>No, this is private information and only Mark will know your answers. Your name will be changed into a number.</p> <p>No school staff members or parents will know who said what in the Focus Group.</p>
<p>1111111q</p> 	<p>How long will the Focus Group take?</p> <p>It might take up to 1 hour to complete the Focus Group in one go.</p> <p>You can have breaks when you want.</p>
	<p>Do I have to take part in this?</p> <p>No, you do not have to take part in the research.</p>
	<p>What if I say “yes”, and then I want to stop?</p> <p>It is OK to stop. We will stop the questions, some of your answers might still be used.</p>



What happens with my answers?

No one will know your answers, because your name will not be used.

Mark will keep the answers so he can better understand about the sex education lessons you had. He will write a report on them. It may appear in a magazine read by experts. But no one will know your name.



Questions?

If you have any questions, please ask the person who gave you this information.



What if I change my mind?

If you change your mind just tell the Mark, or a member of school staff.

You can withdraw from this study at any time, but your answers so far will be used.



Contact for further information:



If you have any questions about the study, please ask the person reading this with you.

Or, you can contact Mark below.



Mark Brown
Tizard Centre
University of Kent
Woodlands
Giles Lane
Canterbury Kent CT2 7LR

APPENDIX J

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Study Two School Information Sheet

School Information Sheet for Participation in Research

What type of sex education programmes are used with students with autism or Asperger's syndrome?

There is a dearth of information on the sex education programmes used with students with autism or Asperger's syndrome. A recent study was carried out with schools who provide for this group, including your own, in relation to the Sex and Relationship Education (SRE) programmes they were currently using. The emphasis of the study was on interviewing the lead person for SRE programmes in each school and attempted to examine a number of key areas:

- How effective is the present sex education programme in relation to teenagers with ASD or Asperger's Syndrome?
- How is this effectiveness measured?
- How is the programme implemented within various schools when pupils with ASD or Asperger's Syndrome are involved?
- What is the programme content and is it necessary to adapt the programme for pupils with ASD or Asperger's Syndrome?

The study included 15 participating schools across London, Surrey and Sussex. The results indicated a need for more specialised programme for individuals with ASD or Asperger's Syndrome than that used with either mainstream pupils or those with an intellectual disability. However, at this stage the study only explored the perceived needs of individuals with ASD or Asperger's Syndrome from the point of view of teachers who were programme planners, and not the views of the individuals themselves.

Purpose of This New Study

The purpose of the present study will be to explore the views of pupils with either Autistic Spectrum Condition or Asperger's Syndrome who have already participated in some form of school SRE programme. To ensure that the pupils have received the full SRE programme, focus groups for each school will be comprised of pupils in the post 16 section of the school. This study is asking schools that participated in the previous study, who have pupils in the post 16 years with the verbal skills and processing ability to participate in a Focus Group. The aim of collecting this information is to provide further information in relation to the

needs of pupils with autism or Asperger's Syndrome in relation to sex education and sexuality. We are inviting a group of your students to take part in this work. Please read this information before you decide.

Why are we asking you?

Your school was chosen because you have participated in the previous study and have shown an interest in participating in further related studies.

Do the pupils have to take part in the research work?

- No, they do not have to take part in this research work.
- However, if you do agree to the pupils participating in the research by allowing a Focus Group of students to be formed, you can change your mind at any point.

What do the pupils have to do, if you agree to them taking part in the research?

As part of the research, Focus Groups will be formed of students who are post 16 within your school and identified by you as possessing the verbal skills to participate in discussion (provided they themselves consent). This approach is being used to examine different aspects of sex education experienced by students within your school.

The Focus Groups explores the experiences of pupils in relation to receiving and participating in sex education programmes that have been used within the school. A set of questions will form the basis of the Focus Groups, but some questions may be difficult or uncomfortable to answer. In this situation the student can decide not to answer the question or discuss it with one of the research team.

What do we want to know?

- We want to know about the sex education programmes being used within your school.

- We want to know the pupils' views on the sex education programmes and how useful they have been

Are there any disadvantages to pupils participating in this research?

- The students may find some questions difficult to answer. In this situation they can discuss the questions with a member of the research team.
- If a student becomes upset during the focus group, they will be supported by a member of the research team to leave the Focus Group and seek support from an appropriate staff member.
- In cases where a disclosure of abuse is made by a student, then support will be provided by a member of the research team to discuss the situation with an appropriate staff member. The research team will be obliged to pass on any details received in relation to disclosure of abuse to the safeguarding lead for the school.

In making your decision, you might want to consider potential reasons to take part/not take part.

- By agreeing to participate in the research, you will help other students with autism or Aspergers syndrome because there will be a better understanding as to the needs of these students and provision of support in similar situations.

What if you don't like the way this work is done?

- You can make a complaint to the Tizard Centre at University of Kent.
- We will give you information about how to complain

Will the information you have provided be kept private?

- Yes. All of the results of this work will be kept locked away and only the research worker and supervisor will be able to look at the files.
- If you or the child withdraws from the research, the information they have provided will be destroyed.

What happens at the end?

- We will provide general written feedback about the results of the research.

- If you request, feedback will also be given verbally.
- The research results will be written up by the research team for dissemination to services, parents and professionals. They may be presented at conferences. No school or pupil names or addresses will ever be given.

Who are the research workers?

- Professor Glynis Murphy and Mark Brown are the research workers.
- Mark is a PhD student at the Tizard Centre. He works as a Special Needs Advisor with people who have various special needs, including Autism and Asperger's Syndrome. Within his work, Mark supports many schools and individuals in the area of sex education and sexuality issues, which is why he is conducting this research.
- Glynis is Mark's supervisor for the PhD, she is a clinical psychologist and is also involved in this area of work.

Has the work been checked?

- The details of the research have been reviewed by the Tizard Centre (University of Kent) ethics committee to ensure that all aspects are appropriate for the subject being researched.
- To ensure that everyone is provided with comprehensive information about the research prior to completion of the questionnaires, the ethics committee and members of the Tizard Centre have reviewed the level of information provided.

Further information:

- Thank you for reading the information about this work.
- You will be given a copy of the information sheet and consent form.
- If you want any extra information, you can call Professor Glynis Murphy (01227 823960) or Mark Brown (07917454573). Or you can write to Professor Murphy at the Tizard Centre, University of Kent, Canterbury, Kent CT2 7LZ or to Mark Brown at the Tizard Centre, University of Kent, Canterbury, Kent CT2 7LZ.

APPENDIX K

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Study Two School Assent Form

School Number:

Participant Identification Number:

SCHOOL ASSENT FORM FOR RESEARCH

Research into the type of sex education programmes used with teenagers with ASD/Aspergers Syndrome.

Name of Researchers: Prof Glynis Murphy, Mark Brown

Please tick \surd the 'YES' box if you agree. Put an X if you don't agree.

YES

I have had read and understood the information sheet

I have asked any relevant questions I wanted to

I understand that our pupils do not have to take part in the research

I understand that I can pull the pupils out at any time without giving a reason

I understand that all information the pupils provide will be in strict confidence

I understand that the Focus Group will be taped and stored in a secure location

I agree that members of the research team can and may contact me to clarify information provided by pupils.

I understand that members of the research team will feedback the results of the research to me, in writing, upon completion of the research

I agree to take part in the research

Name: _____

Post held: _____

School Name: _____

Date: _____

Signature: _____

APPENDIX L

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Study Two Parental Information Sheet

Parent Information Sheet for Participation in Research

What type of sex education programmes are used with students with autism or Asperger's syndrome?

There is a dearth of information on the sex education programmes used with students with autism or Asperger's syndrome. A recent study was carried out with schools whom provided for this group, including your own child's, in relation to the Sex and Relationship Education (SRE) programmes they were currently using. The emphasis of the study was to interview the lead person for SRE programmes in each school and attempt to examine a number of key areas:

- How effective is the present sex education programme in relation to teenagers with ASD or Asperger's Syndrome?
- How is this effectiveness measured?
- How is the programme implemented within various schools when pupils with ASD or Asperger's Syndrome are involved?
- What is the programme content and is it necessary to adapt the programme for pupils with ASD or Asperger's Syndrome?

The study included 15 participating schools across London, Surrey and Sussex. The results indicated a need for more specialised SRE programme for individuals with ASD or Asperger's Syndrome than those used with either mainstream pupils or those with an intellectual disability. However, at this stage the study only explored the perceived needs of individuals with ASD or Asperger's Syndrome from the point of view of programme planners, and not the views of the individuals themselves.

Purpose of This New Study

The purpose of the present study will be to explore the views of pupils with either Autistic Spectrum Condition or Asperger's Syndrome who have already participated in some form of school based SRE programme. To ensure that the pupils have received the full SRE programme, focus groups for each school will be comprised of those pupils in the post 16 section of the school. The study asks schools that have participated in the previous study and who have pupils in the post 16 years with the verbal skills and processing ability to participate in the new study of a Focus Group. The aim of collecting this information is to provide

further information about the needs of pupils with autism or Asperger's Syndrome in relation to sex education and sexuality. We are inviting a group of students from your child's school to take part in this work.

Why are we asking you?

Your child's school was chosen because the school has participated in the previous study and has shown an interest in participating in further related studies.

Does your child have to take part in the research work?

- No, your child does not have to take part in this research work.
- By law, your child can choose for himself or herself whether to take part in the research. This information sheet is simply to let you know that the research is taking place.

What does your child have to do, if they agree to take part in the research?

As part of the research, Focus Groups will be formed of students who are over 16 years of age within your child's school and identified by the relevant staff member as possessing the verbal skills to participate in discussion. This approach is being used to examine different aspects of sex education experienced by students within your child's school.

The Focus Groups explores the experiences of pupils in relation to receiving and participating in sex education programmes that have been used within the school.

What do we want to know?

- We want to know about the sex education programmes being used within your child's school.
- We want to know the pupils' views on the sex education programmes and how useful they have been

Are there any disadvantages to pupils participating in this research?

- The students may find some questions difficult or embarrassing to answer. In this situation they can discuss the questions with a member of the research team.
- If a student becomes upset during the focus group, they will be supported by a member of the research team to leave the Focus Group, if they wish, and seek support from an appropriate staff member.
- In cases where a disclosure of abuse is made by a student, then support will be provided by a member of the research team to discuss the situation with an appropriate staff member. The research team will be obliged to pass on any details received in relation to disclosure of abuse to the safeguarding lead for the school.

Will the information you have provided be kept private?

- Yes. All of the results of this work will be kept locked away and only the research worker and supervisor will be able to look at the files.
- Schools and children who take part will be identified by number only.
- If your child withdraws from the research, the information they have provided will be destroyed.

What happens at the end?

- We will provide general written feedback about the results of the research.
- If you request, feedback will also be given verbally.
- The research results will be written up by the research team for dissemination to services, parents and professionals. They may be presented at conferences. No school or pupil names or addresses will ever be given.

Who are the research workers?

- Professor Glynis Murphy and Mark Brown are the research workers.
- Mark is a PhD student at the Tizard Centre. He works as a Special Needs Advisor with people who have various special needs, including Autism and Asperger's Syndrome. Within his work, Mark supports many schools and individuals in the area of sex education and sexuality issues, which is why he is performing this research.

- Glynis is Mark's supervisor for the PhD, is a clinical psychologist and is also involved in this area.

Has the work been checked?

- The details of the research have been reviewed by the Tizard Centre (University of Kent) ethics committee to ensure that all aspects are appropriate for the subject being researched.
- To ensure that everyone is provided with comprehensive information about the research prior to completion of the questionnaires, the ethics committee and members of the Tizard Centre have reviewed the level of information provided.

Further information:

- Thank you for reading the information about this work.
- You will be given a copy of the information sheet.
- If you want any extra information, you can call Professor Glynis Murphy (01227 823960) or Mark Brown (07917454573). Or you can write to Professor Murphy at the Tizard Centre, University of Kent, Canterbury, Kent CT2 7LZ or to Mark Brown at the Tizard Centre, University of Kent, Canterbury, Kent CT2 7LZ.

APPENDIX M

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Study Two Parental Assent Form

School Number:

Participant Identification Number:

PARENTAL ASSENT FORM FOR RESEARCH

Research into the type of sex education programmes used with teenagers with ASD/Aspergers Syndrome.

Name of Researchers: Prof Glynis Murphy, Mark Brown

Please tick \checkmark the 'YES' box if you agree. Put an X if you don't agree.

YES

I have had read and understood the information sheet

I have asked any relevant questions I wanted to

I understand that my child does not have to take part in the research

I understand that I can pull my child out at any time without giving a reason

I understand that all information provided will be in strict confidence

I understand that the Focus Group will be taped and stored in a secure location

I understand that members of the research team will feedback a summary of the research results to me and my child, in writing, upon completion of the research

I agree to take part in the research

Name: _____

School Name: _____

Date: _____

Signature: _____

APPENDIX N

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Study Three Ethical Approval Letter

Tizard Ethics Feedback Form

Student Name:	Mark Brown	
Supervisor:	Glynis Murphy & Michelle McCarthy	
Title:	<i>Sexuality and Autistic Spectrum Disorder– Support and Education</i>	
<p>The Tizard Ethics Committee had considered the amendments and confirm that this proposal has ethical approval.</p> <p>Signed: J.Ruffels Date: 02.03.17</p> <p>On behalf of Tizard Ethics Committee</p>		
Alterations approved by Supervisor	Signature	Date
Final approval On behalf of Tizard Ethics Committee	 Michelle McCarthy Signature	Date 02.03.17

APPENDIX O

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Study Three SRE Pilot Programme Outline

SRE Course Outline

The course utilises visual methods, including video vignettes to provide participants to ability to explore actual situations. Each session lasts 45 minutes and involves an additional staff member; either from the school or an external individual with the appropriate experience, to assist in smaller group work.

Session One – Foundation Sex Education

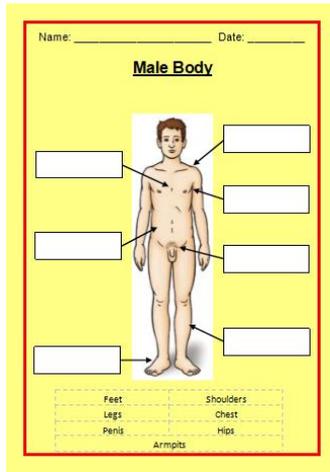
Although it is assumed that all participants would have received some form of Sex and Relationship Education, the level of knowledge acquisition and teaching methods may vary depending upon the individual and the support they were provided. Therefore, Session One is aimed at ensuring that all participants possess the same foundation knowledge in regards to body parts, puberty changes and sexual activities, and any queries relating to the physical side of sex and relationships are explored.

Aims:

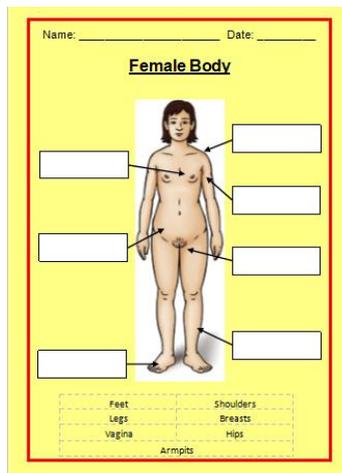
- To ensure that all group members know body part names,
- To support those feeling anxious about sexual matters
- To agree acceptable terms for body parts

Overview of session activities:

1. As this is the first session time should be taken to introduce everyone and to outline what the sessions will involve.
2. Explain that for the work this week you are going to talk about **body part names**. Tell people you will start with the easy ones (they may be embarrassed/anxious). And say you will do a man first and then a woman next.
3. Have the image of a **man's** body (can be on paper, displayed on a screen or both) and one facilitator ready to support group members.



4. Ask for volunteers to show where each part of the man's body are. Encourage the volunteer to get up and point to and label the parts.
5. Vary it a bit by pointing some parts out yourself and asking group members what they are called, and then get them to come up and label them
6. Repeat this process for the picture of a woman's body.



7. During this process, it is important to remind participants about the private part not visible (the bottom). Once the private sexual parts are identified, then participants should discuss any other parts of their own bodies which they dislike being touched (e.g. arms, etc).

8. Following this activity, the participants are asked to provide slang wording for various body parts, specifically PENIS, VAGINA and BREAST. The group members may be embarrassed - encourage them to say any of the slang names they know (and then add all of them to the flip chart). The group usually start by being reluctant but end up by thinking up a large number of names and it becomes a fun game. Many participants may have misconceptions re body parts and function. Therefore, it is useful to state the body parts and their function e.g. penis is for urination, masturbation, sex - not loads of detail, just a few words. Foster a healthy view/approach to sex/exploring own body, therefore highlighting we can get nice feelings from these parts so it is not merely about function.
9. Once the words have been identified, it is important to discuss with participants about where it is acceptable and not acceptable to use the slang terms. Agree the names you will use in the group (usually the group agree 'penis', 'bottom' and 'balls' for men, 'breasts' and 'vagina' for women, 'pubic hair' for both). Using correct names may be better for learning.

Session Two and Three – Relationships

These sessions will explore all aspects of relationships including:

- **different types of relationships that it is possible to have e.g. family, romantic, professional, etc.**
- **what type of behaviours are acceptable in different relationships, including sexual relationships.**
- **good ways of getting to know someone and how to go about developing and maintaining friendships and relationships.**
-

The sessions will utilise video vignettes to enable participants to talk about what they see and explore various aspects of building and maintaining relationships.

Aims:

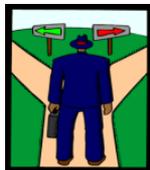
- To help the group to think about the different types of relationships (categories, such as family, friends, staff, etc)
- To consider who there are in social networks, and how 'close' we feel to each one
- To think about who helps and who doesn't in networks

Materials:

1. Joe's story powerpoint
2. Relevant handouts

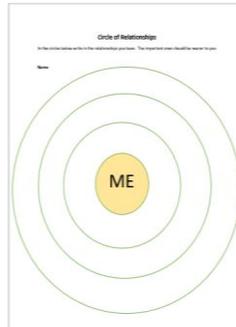
Session activities:

1. Remind the group of last week's work (put up the pictures to help).
2. Introduce the group to the Man At The Crossroads. Discuss how when we make decisions there are two pathways. Each pathway has its own consequences, whether it is Positive (Green Pathway) or Negative (Red Pathway). Discuss how the image will be used throughout the rest of the sessions to highlight the choices people can make.



3. Relationships- introduce the idea that the group are going to think about relationships between people – like friends, families, girlfriends and boyfriends, staff.

- Using the Circle of Relationships (See below), get each participant to identify the various people they have a relationship with (including parents, siblings, teachers) and how close they are to the individual. Include Police, Doctor and Nurse.

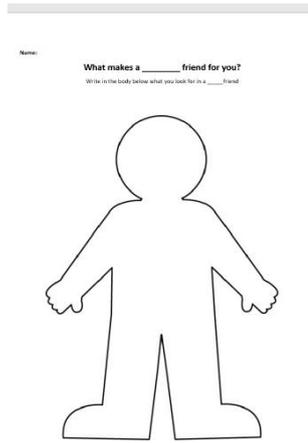


If participants find the concept difficult on paper, then it is possible to use the room as the paper and give participants labels for different people and physically stand in the circles. This can then be transferred to the paper for later exercise.

- Following this exercise, the group should be shown the “Joe” powerpoint. (Need to be sensitive about family issues for some- may have family members who have abused participants, non-contact fathers, family members in prison, etc. network).
- Think about Joe’s network- Who made it more likely that **Joe** would go the Good Way (refer to visual), who made it more likely that **Joe** would go the Bad Way

END SESSION

- Remind the group of last week’s work (put up the pictures to help).
- Using the image below, get participants to think about what makes a Good Friend and a Bad Friend. They should be encouraged to feedback to the group so that a list can compiled from everyone’s ideas.



3. Following this exercise, discussion should commence in relation to what an individual is able to do with each person in their Circle of Relationships. Before returning back to the Circle, the NSPCC “Pants Rule” film clip should be shown. This is a light hearted but memorable video which can start conversation about private parts.

4. Following the video and discussion, participants should be encouraged to review their Circle of Relationships. The following list of actions should be colour coded and marked against each person that it is relevant to:
 - Talk to
 - Shake Hands
 - Hug
 - Kiss on cheek
 - Kiss on lips
 - Touch Private Parts
 - Have Sex

When going through the list, it will be important to refer to the Pants Rule regarding doctors and nurses. Discussion should take place about when it would be appropriate for such people to touch the participants’ private parts. This is to ensure that the

participant understands that there may be some occasions when strangers need to touch their private parts.

5. Introduce the group to the idea of sexual relationships and sexual orientation. Encourage participants to contribute to developing a list of different types (e.g. heterosexual, homosexual, asexual), include initial discussion surrounding consent but highlight that this will be discussed in more detail next session.

Session Four and Five – Consent and Legal Issues

These sessions will centre upon the legal issues associated with socio-sexual side of growing up, including:

- **Consent will be explored via video vignettes (e.g. Clips from This Is Abuse government campaign) to highlight how consent can be appropriately and inappropriately (coerced) gained from individuals. In regards to consent, the sessions will cover what consent means; legal age of consent, verbal and nonverbal consent**
- **The legal aspects will be explored in relation to the law and consequences, including prison, using appropriate visual approaches as well as the use of “story telling” to facilitate participants to progress through the appropriate choices available.**

Aims:

- To introduce consent, and its elements
- To reinforce the idea of Good way/Bad way choices
- To introduce the idea of Good side/Bad side in relation to consent

Materials:

1. Consent rules powerpoint
2. Consent scenarios- *below in session plan*

Activities:

1. Remind the group of last week's work (put up the pictures to help).
2. **Consent** : introduce consent by exploring with participants what they understand about it.

Explore the practical use of consent; both in relation to sexual activities and general consent (e.g. going on a trip).

Ask how can people say "No"? (*by saying "No", how their face looks, how their body is*). Utilise images from *Puberty & Sexuality for Children and Young People with a LD* by Children's LD Nursing Team, Leeds (2009) to demonstrate scenarios. This should be explored by participants.

3. Look at the Consent rules using the powerpoint to explore the elements and also visual consent sheet

To do sexual things with someone you and the other person must:

- *Both be 16 years old or over*
- *Both say yes to doing sexual things*
- *Both have good body language ie show you want to do it by what you do, not just what you say*
- *Both not have taken drugs or be drunk*

Look at “*Tea as Consent*” film (clean version). This provides participants with a fun, memorable way of exploring the concept. It enables a reference point to prompt participants in later sessions.

4. **Consent in action activity:**

Present scenarios on screen/flipchart. If you prefer you can do role play (but see below) or use pictures that show the scenarios, or puppets, etc). Note key information on age etc on flip chart.

This activity has helped young people understand the tricky concept of consent - and to understand that all 4 elements must be OK/on green for consent to be given/OK.

Consent scenarios :

In the following scenario’s, apart from the first one and last one which are “OK”, in the other scenarios, 3 of the consent rules are “OK” and 1 is “not OK”, therefore consent not properly given.

If using role plays for the scenarios, need to think carefully about how to create distance and ensure young people understand it is not real- do this by creating a stage as in a performance of a play/TV programme, preparation/debriefing etc

Scenario One: 2 men both 18 years old

- Been together for a year
- Both want to have sex /get intimate- touch each other’s private parts
- Both happy to do it
- Both look happy
- Both sober / no drugs

Scenario 2: 17 year old boy babysitting a 10 yr. old girl:

- Boy touches the girl on the bottom or kisses the girl
- Girl smiles
- Boy asks if it is ok and she says yes
- They are both sober and have not taken drugs

Scenario 3: 2 x 16 year old boys:

- Dating for a month
- Had sex before
- Both seem happy smiling
- Both kissing on the sofa (positive body language)
- One boy wants to take it further and have sex, the other says no

Scenario 4: 2 18 year olds, one boy, one girl:

- Been on 2 dates
- Kissing –both seem happy to kiss and the both have said yes
- No drugs/drink
- The boy is hugging the girl tightly and the girl is looking frightened and pushing the boy away

Scenario 5: A 17 year old girl and a 16 year old boy:

- Met at a party
- Both want to have sex and say yes
- Kissing each other and cuddling
- Whilst at the party they go upstairs to have sex
- They are both drunk from alcohol at the party

Scenario 6: 2 women, one 19 yrs old, one 18 years old:

- Have been on a couple of dates
- Both like each other and want to kiss
- Both say yes and are close to each other
- Both sober / no drugs

For each scenario, ask if each person is going the Good Way or the Bad Way? (use the visual)

Show the “*Abuse in Relationship*” video within which consent is coerced through aggression to allowed participants to see how such coercion can occur. Discuss the situation.

Remind group members of the Good Side/Bad Side visual and ask who is showing his Good Side/ Bad Side? (use the visual).

Discuss consequences of not consenting, going the Bad Way, showing the Bad Side, e.g. getting into trouble with the police; prison; going on the Sex Offenders Register; being subject to restrictions/not being able to do things; may lose contact with family; move/change school/college.

Session Six– Public/Private

These sessions will look at this topic from the point of view of a person’s body as well as the environment.

The former will utilise appropriate visual methods to look at where such body parts are, including any non-sexual parts that individual participants may class as their own private parts. In addition, the discussion will link back to the Relationships sessions in regards to what type of touch and interaction can occur with the various people that have been identified as being in a relationship with participants.

The latter aspect; environment, will also utilise appropriate visual methods including photographs and video, to identify types of location and explore them in detail. Associated

with this will be the identification of where it is appropriate to participate in various activities, including those of a sexual nature. There will also be discussion surrounding public and private in regards to the use of technology, particularly webcam, etc, in various locations.

Aims:

- To explore the concept of Public/Private in relation to body parts and locations, including consequences to actions
- To demonstrate how consent relates to the subject.
- To reinforce the idea of Good way/Bad way choices

Materials:

1. Consent rules sheet
2. Man and body pictures from previous sessions
3. Location images

Activities:

1. Remind the group of last week's work (put up the pictures to help).
2. Using Flipchart/Screen to review the issue of consent. Write up different ages and sexes (e.g. Man 16 Women 18; Man 15 Man 21) to ensure that participants have remembered the relevant aspects to consent.

3. Re-introduce the body images from session one. Explore with participants what are public or private body parts. Remember to include those that cannot be seen such as the bottom.
4. Discuss with participants whether there are any non-sexual parts that they do not like being touched (e.g. shoulders, hair, etc) and if they feel confident to do so explore why.
5. Discuss who could touch the private parts and what situations these could involve. This reinforces previous sessions as well as allow further discussion surrounding the legal aspects.
6. Introduce images of locations. These could be cartoons or photographs, but should include rooms in the home (kitchen, bathroom, bedroom, lounge), locations out in the community including swimming pool and a car (there should be two pictures involving a car; one in a forest and one in high street/public road).
7. Participants should discuss each picture and explore whether there are any private areas and what the consequences would be if partaking in the wrong activities. Specific areas of discussion should include:
 - Bedroom – curtain/blinds closed, door closed, no-one else in room and not using tablet/computer/phone to Facetime/Skype someone whilst naked.
 - Bathroom- curtain/blinds closed, door closed, no-one else in room
 - Swimming Pool – Discuss both the pool area and changing rooms
 - Public Toilet – Discuss urinal area and cubicles.

Session Seven and Eight– Online and Technology Issues

This will continue the exploration within the previous section as well as the legal issues. The session will utilise “story telling” to explore issues such as the law, coercion and grooming.

Aims:

- To deepen understanding of respect, consent and consequences
- To consider what is OK and what is not OK on internet and social media
- Consider who is being harmed by social media and internet
- To know what is legal and what is illegal

Materials:

1. Big Rules of Sex
2. Share Aware animations: streamed from NSPCC
 - I saw your willy (photo sharing, 30 sec)
<http://www.nspcc.org.uk/preventing-abuse/keeping-children-safe/share-aware/>
 - Just Send It video
 - Consequences assembly for 11 16 years video
3. Internet safety visual (A3 and A4)- Internet, Mobile Phone, App and Games Console safety
4. Good Way/Bad Way including Man At Crossroads

Activities

1. Remind the group about last week's work (with some pictures if helpful).
2. Ask them what the internet is, if/how/what they use it (computer, ipad, phones/games, email, school or college stuff, TV, Music, films, photos, Facebook,

other?). List these on a flip chart, find out about who uses Facebook and other social media . If porn is mentioned, put this up and say will talk more about that next session. Ask what Social Media they use? Ask about any others they've heard of.

Look at a couple of categories briefly, and begin to get views of what is OK and what is not OK- Eg writing/reading something friendly versus something nasty; seeing something fun, seeing something cruel/mean. Ask, do you know who you are talking to on-line, do you know who can see your pictures on line?

3. Hand out and look at the 5 *Internet, Mobile Phone, App and Games Console Safety rules* to go through the following scenarios- use flip chart / role plays/sculpts:

Scenario i) A 16 year old boy was in a chat room and met a girl who called herself "Partygirl". He described how they went on to talk about everything. After chatting, the boy gave the girl his email address, added her on Facebook, and told him where he lived. After a while they exchanged pictures, he thought she looked like a nice, normal girl.

After a month they planned to meet up. The boy arrived with a picture of her so he could recognise her. A man came up to boy. He said he was the girl's granddad. The boy asked what the man knew about him....he knew everything. The boy ran away. He never heard from "Partygirl" again...

Refer to rules 1, 2 and 3 Use "Are they really who they say they are" visual. Talk about how they can make sure

Show "Consequences assembly for 11 16 year" which explores the hazards of posting online and how coercion/blackmail can occur from the information posted

Discuss why people may talk to people on line they don't know (fun, feeling lonely, want new friends, everybody's doing it, new experience/risk ie what teenagers do etc). What might happen? What could they do instead which is OK, safe?

Show “I saw your willy” (photo sharing, 30 sec) <http://www.nspcc.org.uk/preventing-abuse/keeping-children-safe/share-aware/> if appropriate (helpful for those with quite substantial impairments and to reinforce the message, the character is young- but this is important for the young people to think about this being an issue across all ages, could be used as introduction

Discuss why people may take photos of body parts and send them to a friend, (sexting): to have a laugh/fun, want to show they like someone, feeling insecure/under pressure/lonely, want to seem grown up, “everybody’s doing it”, new experience/risk ie what teenagers do etc). Ask YPs what might happen? What could they do instead which is OK, safe?

Show “Just Send It” Video. Discuss what was happening within the video and the potential impact on each individual. This maybe done at the end of the video or during the showing at key points (e.g. peer pressure, what could a better choice look like)

4. Discuss the consequences to online actions, whether sending messages or pictures. Highlight areas such as:
 - Once sent, a picture unlikely to ever be 100% deleted (consequences- bullying, embarrassment, parents, police, future eg getting a job)
 - If under 18 – it’s illegal – *Indecent images* of under 18s are illegal. *Indecent?* = basically *if it’s*:
 - *Naked*
 - *a topless girl*
 - *contains genitals or sex acts, including masturbation,.....*then it will be *indecent*.

It is illegal to *take, possess or share 'indecent images' of anyone under 18 even if you're the person in the picture.*

Remember - if you wouldn't show it to your parents or your gran, you probably shouldn't share it online!

- They might show or send it to other people
- Even if in a relationship.....Imagine a bad break up, they might want to hurt you
- You might break a Big Rule of Sex
- If someone sends you photos, videos or messages that worry or upset you – tell trusted adult

5. Ask if there are any other rules to add to avoid trouble on the internet/social media? What things can they do differently to make sure they have safe fun online? Provide updated version of consent rules to include online aspects

1. extend internet, phone and games console safety, discuss pornography (what it is, what is legal, issues)

2. Ok/not OK Go through below sexting examples (don't have to do all) :

Look at consequences for the person, their family, friends, others in their networks, consequences now (in trouble with police, court, sex offenders register, restrictions to freedom, trust etc), and consequences later (restrictions, going to college/getting a job, making new friends/girlfriends etc).

Also, look at consequences from the perspective of the different characters- the “perpetrator”, and the “victims”

Tom who was 32, claimed to run a modelling agency. Using Facebook, he got girls to take nude pictures of themselves and send them to him. He paid for the pictures girls sent. Police estimate he had at least 80 victims. He got 10 years on prison.

A 12 year old girl took sexual pictures of herself and sent them to a 22 year old male she had been talking to on Xbox. The girl said she was 19. The man was shocked. Police didn't believe him, he went to prison for 4 years.

A girl, 13, sent a topless photo of herself to her boyfriend, who was 14. When they broke up, the boy sent the photo to his friends, by the end of the week over 200 students had received the picture. The police seized over 150 cell phones from students. The boy was sent to a young offenders institute, the girl was given a caution.

Two girls, who were school friends got mad at each other. They had been friends and had access to nude photos of each other. Girl A showed a nude photo of Girl B to another girl. Girl B thought the photo had been shown to many people. To get even, she sent a picture of Girl A's breasts to several boys.

A 16 year old accidentally uploaded a nude picture of herself to Instagram. When she realized this, she deleted the image, but a boy from her school had already downloaded it. He threatened to send to the rest of the school if she did not send him more nude pictures. When the girl refused, the boy sent the picture to about 100 people. The boy, who was a straight A student went to a young offenders institute.

A 15 year old girl and 16 year old girl had been friends and schoolmates but had a falling out. The 15 year old created a fake online profile of a boy who appeared to be interested in the 16 year old. The fake boy asked for a naked picture of the 16 year old, which she sent. The 15 year old girl sent the image to her friends, eventually 50-100 people saw it. The 15 year old girl was arrested for sharing child pornography.

Two 15 year old boys, who had been each other's boyfriend for a couple of weeks, sent sexual pictures and videos of themselves naked to each other. Both went to court and were given 20 hours of community service.

Discuss/recap why people may send/resend photos of body parts-sexting, (have a laugh/fun, think it's cool, want to embarrass someone, "everyone is doing it"/new experience/risk ie what teenagers do, feeling pressured etc) or talk to people online/make new "online friends" (feeling lonely, feeling bored, have fun, think it's cool, "everyone is

doing it"/new experience/risk ie what teenagers do etc. What might happen ? What could they do instead which is OK, safe?

6. Pornography:

Ask about why/when/how do people look at pornography? (feeling lonely, feeling bored, have fun, think it's cool, "everyone is doing it", pressured by others, want to learn, feel sexy; magazines, computer, with mates, alone, with girlfriend/boyfriend)

What is pornography?-

1. Adult pornography- sexually explicit images and videos with consenting adults aged 18 or over – this is legal
2. Illegal : 'indecent images' (ie sexual images) of anyone under 18 - it is illegal to *take, possess or share pictures and/or video*
3. Illegal: Extreme sexual acts – eg rape or other harm

2 & 3 are illegal to protect children and young people, and adults from harm. Police can seize your computer and look at what you have been doing.

What might be not Ok about pornography? Think about effects on those watching, and those in the films/pictures, consequences. Discuss the following aspects about pornography to ensure that participants are fully aware of what is pornography

- *Illegal to look at pictures/ porn showing under 18s; recap consequences (police, court, sex offender register etc)*
- *With adult porn, they are acting it's a performance*

- *Often pretending to enjoy it*
- *Edited to look more fun*
- *Often only about what the man wants – don't show consent? Do show Violence*
- *Rarely wear condom – but you must!*
- *Bodies*
 - *Not all men are muscly*
 - *Porn often shows men with a larger than normal penis*
 - *Not all women have large breasts – come in all shapes and sizes*
 - *Lots of men and women don't shave their pubic hair*
- *So, porn not really showing anything to help folk learn about healthy sex and relationships*

Session Nine – Summary

This final session will enable participants to discuss and clarify any issues that have been discussed as well as any topics that may have arisen during the course.

Aims:

- To explore the concept discussed within the previous sessions
- To ascertain how much knowledge has been retained
- To reinforce all the ideas developed during the previous sessions.
- To discuss the topic of STI and contraception

Materials:

1. Consent rules sheet
2. Sex/Relationship/Law quiz

3. Have all previous materials in case they are needed for discussion
4. Sexual Health powerpoint and condom training kit

Activities:

1. Remind the group of last week's work (put up the pictures to help).
2. Go through the issue of sexual health and why use contraceptions.
3. Demonstrate how to use a condom with the kit (false penis and condoms) with the list of what to do. Also relate this back to the issues of relationships, consent and the law to ensure that participants are fully aware of how it all connects.
4. Go through the quiz. This can be done with paper and pen or just by asking people to say the answer.
5. Depending upon the quiz results, the remainder of the session will explore any areas highlighted as requiring some additional work.

APPENDIX P

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Study Three Participant Information Sheet



Participant Information Sheet

Title of Study: Adapted sex education programmes for students with autism

Name of Researcher: Mark Brown

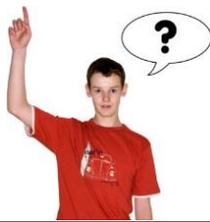
	<p>You are being invited to take part in Mark's research.</p>
	<p>Mark is studying for his doctorate at the University of Kent.</p> <p>Mark's research is to run a sex education programme for pupils with autism to help them be safer in relationships and life.</p>
	<p>Mark has some new ways of teaching sex education and relationships for students with autism. He wonders if you would like to take part in a programme in your school?</p>
	<p>In the programme, there will be other pupils from your school all taking part as well. Some of you may not be in the programme, but will have it later on.</p> <p>Mark will ask you some questions before and after the programme to see what you thought of it. These questions will be recorded and kept safe for Mark and his supervisor.</p>

	<p>What will the programme include?</p> <p>It will include talking about types of relationships and how to enjoy relationships. It will talk about keeping safe when you are with other people.</p> <p>It will talk about keeping safe when using the internet.</p>
	<p>What happens if I say “yes” to doing the programme?</p> <p>It means that you and a group of pupils from your school will meet with Mark in a quiet room at school.</p> <p>Mark will support you in taking part in the programme</p>
	<p>What if I have difficult feelings when taking part in the programme?</p> <p>If you feel upset, angry or uncomfortable you can talk to Mark or you can talk to a member of school staff.</p>
	<p>Who might see what happens?</p> <p>The programme will be private and only known to Mark.</p>

	<p>But if you talk about you or someone else being hurt, we might have to tell someone, like your class teacher.</p> <p>We will tell you if we need to do this.</p>
	<p>Will other people know who I am?</p> <p>No, this is private information and only Mark will know your answers to questions. Your name will be changed into a number.</p> <p>No school staff members or parents will know who said what in the programme.</p>
	<p>How long will the programme take?</p> <p>The programme will include 9 sessions. Each will be 45 minutes long and will happen in school time.</p> <p>You can have breaks when you want.</p>
	<p>Do I have to take part in this?</p> <p>No, you do not have to take part in the research.</p>
	<p>What if I say “yes”, and then I want to stop?</p> <p>It is OK to stop. If you decide to stop doing the programme you can leave the group.</p>
	<p>What happens with the results?</p> <p>No one will know what you have said during the programme.</p>



Mark will keep what you say private so he can better understand about how the programme went. He will write a report on it. It may appear in a magazine read by experts. But no one will know your name or the name of the school.



Questions?

If you have any questions, please ask the person who gave you this information.



What if I change my mind?

If you change your mind just tell the Mark, or a member of school staff.



You can withdraw from this study at any time, but your answers so far will be used.



Contact for further information:



If you have any questions about the study, please ask the person reading this with you.

Or, you can contact Mark below.



Mark Brown
Tizard Centre
University of Kent
Cornwallis North East
Canterbury
Kent CT2 7NF

APPENDIX Q

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Study Three Participant Consent Form



Pupil Consent Form

Title of Study: Adapted sex education programmes for teenagers with Autistic Spectrum Disorder

Name of Researcher: Mark Brown

	You are being invited to take part in Mark's research.	
	If you agree to what is being said then please tick <input type="checkbox"/> the box. If you don't agree then put a X in the box	
	I have read and understood the information sheet	
	I have asked the questions I wanted to	

	<p>I know I do not have to take part in the programme</p>	
	<p>I know I can leave the programme without giving any reasons why.</p>	
	<p>I know everything I say will be private unless I tell the researcher that I or someone else is in danger of harm</p>	
	<p>I know the researchers will tell me about the results of the programme when they are all finished</p>	
	<p>I agree to take part in the programme</p> <hr style="border: 1px solid gray;"/>	

Name:

Date

APPENDIX R

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Study Three Parental Information Sheet

Parent Information Sheet for Participation in Research

Adapted sex education programmes for students with autism

There is a dearth of information on the sex education programmes used with students with autism. Two recent studies were carried out with a number of schools who provide for this group, including your own son/daughter's school, in relation to the Sex and Relationship Education (SRE) programmes they were currently using. The emphasis of these studies was on interviewing the lead person for SRE programmes in each school and running a Focus Group with some of the students in an attempt to examine a number of key areas:

- How effective is the present sex education programme in relation to teenagers with ASD?
- How is this effectiveness measured?
- How is the programme implemented within various schools when pupils with ASD are involved?
- What is the programme content and is it necessary to adapt the programme for pupils with ASD?

The study included 15 participating schools across London, Kent, Surrey and Sussex. The results indicated a need for more specialised programme for individuals with ASD than that used with either mainstream pupils or those with an intellectual disability.

Purpose of This New Study

The purpose of the present study will be to pilot and evaluate an adapted SRE programme with pupils who are diagnosed with Autistic Spectrum Condition. The aim of the intervention is to provide an appropriate SRE programme to meet the needs of pupils with autism in relation to sex education and sexuality. A summary of the sessions is attached. We are inviting a group of students aged 15 years from your child's school to take part in this work. Please read this information before you decide if we can include your son/daughter.

Why are we asking you?

Your child's school was chosen because they have participated in the previous study and have shown an interest in participating in further related studies.

Does your child have to take part in the research work?

- No, your child does not have to take part in this research work.
- However, if you do agree to your child participating in the research by allowing them to take part in an SRE programme pilot to occur within their school, you can change your mind at any point.

What do the pupils have to do, if you agree to them taking part in the research?

As part of the research, students who are aged 15 years within your child's school will take part in a 9 week SRE programme that explores socio-sexual areas of development. This approach is being used to develop an appropriate SRE programme for students with autistic spectrum disorder within schools. In addition, your child will be required to complete a brief interview prior to and after the intervention as well as 3 months after completion. These interviews will be part of an assessment in relation to how the programme has worked. Initially the pupils will be divided into two groups; one will be part of the new programme whilst the other group will be part of the old programme. Following completion of the programme and the second interview, those pupils who were part of the old programme, will be given the new programme.

The SRE programme is based upon information obtained within the previous studies and explores a range of social areas linked with sex and sexuality. A set of questions will form the basis of the interviews, but some questions may be difficult or uncomfortable to answer. In this situation your child can decide not to answer the question or discuss it with one of the research team.

What do we want to know?

- We want to know whether the SRE programme that has been developed enables the pupils to effectively improve their knowledge in regards to sex and sexuality.

Are there any disadvantages to pupils participating in this research?

- Your child may find some questions difficult to answer or topics difficult to participate in. In this situation they can discuss the issues with a member of staff or with the research team.
- If your child becomes upset during the SRE programme, they will be supported by a member of the research team to leave the programme and/or seek support from an appropriate staff member.
- In cases where a disclosure of abuse is made by a student, then support will be provided by a member of the research team to discuss the situation with an appropriate staff member. The research team will be obliged to pass on any details received in relation to disclosure of abuse to the safeguarding lead for the school.

In making your decision, you might want to consider potential reasons to take part/not take part.

- By agreeing to participate in the research, you will help other students with autism because there will be a better understanding as to the needs of these students and provision of support in similar situations, as well as the development of an appropriate programme.

What if you don't like the way this work is done?

- You can make a complaint to the Tizard Centre at University of Kent.
- We will give you information about how to complain

Will the information you have provided be kept private?

- Yes. All of the results of this work will be kept locked away and only the research worker and supervisor will be able to look at the files.
- Children will be given an identification number so that their names will not appear on their data.
- If you or your child withdraws from the research, the information they have provided will be destroyed.

What happens at the end?

- We will provide general written feedback about the results of the research.

- If you request, feedback will also be given verbally.
- The research results will be written up by the research team for dissemination to services, parents and professionals. They may be presented at conferences. No school or pupil names or addresses will ever be given.

Who are the research workers?

- Professor Glynis Murphy and Mark Brown are the research workers.
- Mark is a PhD student at the Tizard Centre. He works as a Special Needs Advisor with people who have various special needs, including Autism and Asperger's Syndrome. Within his work, Mark supports many schools and individuals in the area of sex education and sexuality issues, which is why he is conducting this research.
- Glynis is Mark's supervisor for the PhD, she is a clinical psychologist and is also involved in this area of work.

Has the work been checked?

- The details of the research have been reviewed by the Tizard Centre (University of Kent) ethics committee to ensure that all aspects are appropriate for the subject being researched.
- To ensure that everyone is provided with comprehensive information about the research prior to completion of the questionnaires, the ethics committee and members of the Tizard Centre have reviewed the level of information provided.

Further information:

- Thank you for reading the information about this work.
- You will be given a copy of the information sheet and consent form.
- If you want any extra information, you can call Professor Glynis Murphy (01227 823960) or Mark Brown (07917454573). Or you can write to Professor Murphy at the Tizard Centre, University of Kent, Cornwallis North East, Canterbury, Kent CT2 7NF or to Mark Brown at the Tizard Centre, University of Kent, Cornwallis North East, Canterbury, Kent CT2 7NF.

APPENDIX S

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Study Three Parental Assent Form

School Number:

Participant Identification Number:

PARENTAL CONSENT FORM FOR RESEARCH

Adapted sex education programmes for teenagers with ASD

Name of Researchers: Prof Glynis Murphy, Mark Brown

Please tick \checkmark the 'YES' box if you agree. Put an X if you don't agree.

YES

I have had read and understood the information sheet

I have asked any relevant questions I wanted to

I understand that my child does not have to take part in the research

I understand that I can pull my child out at any time without giving a reason

I understand that all information provided will be in strict confidence

I understand that the assessment interviews will be taped and stored in a secure location

I understand that members of the research team will feedback a summary of the research results to me and my child, in writing, upon completion of the research

I agree to take part in the research

Name: _____

School Name: _____

Date: _____

Signature: _____

APPENDIX T

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Study Three School Information Sheet

School Information Sheet for Participation in Research

Adapted sex education programmes for students with autism

There is a dearth of information on the sex education programmes used with students with autism. Two recent studies were carried out with a number of schools who provide for this group, including your own, in relation to the Sex and Relationship Education (SRE) programmes they were currently using. The emphasis of these studies was on interviewing the lead person for SRE programmes in each school and running a Focus Group with some of the students in an attempt to examine a number of key areas:

- How effective is the present sex education programme in relation to teenagers with ASD?
- How is this effectiveness measured?
- How is the programme implemented within various schools when pupils with ASD are involved?
- What is the programme content and is it necessary to adapt the programme for pupils with ASD?

The study included 15 participating schools across London, Kent, Surrey and Sussex. The results indicated a need for more specialised programme for individuals with ASD than that used with either mainstream pupils or those with an intellectual disability.

Purpose of This New Study

The purpose of the present study will be to pilot and evaluate an adapted SRE programme with pupils who are diagnosed with Autistic Spectrum Condition. The aim of the intervention is to provide an appropriate SRE programme to meet the needs of pupils with autism in relation to sex education and sexuality. We are inviting a group of your students aged 15 years to take part in this work. Please read this information before you decide.

Why are we asking you?

Your school was chosen because you have participated in the previous study and have shown an interest in participating in further related studies.

Do the pupils have to take part in the research work?

- No, they do not have to take part in this research work.
- However, if you do agree to the pupils participating in the research by allowing an SRE programme pilot to occur within your school, you can change your mind at any point.

What do the pupils have to do, if you agree to them taking part in the research?

As part of the research, students who are aged 15 years within your school, as identified by you, will take part in a 9 week SRE programme that explores socio-sexual areas of development. This approach is being used to develop an appropriate SRE programme for students with autistic spectrum disorder within schools. In addition, each student will be required to complete a brief interview prior to and after the intervention as well as 3 months after completion. These interviews will be part of an assessment in relation to how the programme has worked. Initially the pupils will be divided into two groups; one will be part of the new programme whilst the other group will be part of the old programme. Following completion of the programme and the second interview, those pupils who were part of the old programme, will be given the new programme.

The SRE programme is based upon information obtained within the previous studies and explores a range of social areas linked with sex and sexuality. A summary of the sessions is attached for your information. A set of questions will form the basis of the interviews, but some questions may be difficult or uncomfortable to answer. In this situation the student can decide not to answer the question or discuss it with one of the research team.

What do we want to know?

- We want to know whether the SRE programme that has been developed enables the pupils to effectively improve their knowledge in regards to sex and sexuality.

Are there any disadvantages to pupils participating in this research?

- The students may find some questions difficult to answer or topics difficult to participate in. In this situation they can discuss the issues with a member of the research team.
- If a student becomes upset during the SRE programme, they will be supported by a member of the research team to leave the programme and/or seek support from an appropriate staff member.
- In cases where a disclosure of abuse is made by a student, then support will be provided by a member of the research team to discuss the situation with an appropriate staff member. The research team will be obliged to pass on any details received in relation to disclosure of abuse to the safeguarding lead for the school.

In making your decision, you might want to consider potential reasons to take part/not take part.

- By agreeing to participate in the research, you will help other students with autism because there will be a better understanding as to the needs of these students and provision of support in similar situations, as well as the development of an appropriate programme.

What if you don't like the way this work is done?

- You can make a complaint to the Tizard Centre at University of Kent.
- We will give you information about how to complain

Will the information you have provided be kept private?

- Yes. All of the results of this work will be kept locked away and only the research worker and supervisor will be able to look at the files.
- If you or the child withdraws from the research, the information they have provided will be destroyed.
- Information on children will be anonymised, i.e. they will be allocated an ID number so their name does not appear on their data

What happens at the end?

- We will provide general written feedback about the results of the research.

- If you request, feedback will also be given verbally.
- The research results will be written up by the research team for dissemination to services, parents and professionals. They may be presented at conferences. No school or pupil names or addresses will ever be given.

Who are the research workers?

- Professor Glynis Murphy and Mark Brown are the research workers.
- Mark is a PhD student at the Tizard Centre. He works as a Special Needs Advisor with people who have various special needs, including Autism and Asperger's Syndrome. Within his work, Mark supports many schools and individuals in the area of sex education and sexuality issues, which is why he is conducting this research.
- Glynis is Mark's supervisor for the PhD, she is a clinical psychologist and is also involved in this area of work.

Has the work been checked?

- The details of the research have been reviewed by the Tizard Centre (University of Kent) ethics committee to ensure that all aspects are appropriate for the subject being researched.
- To ensure that everyone is provided with comprehensive information about the research prior to completion of the questionnaires, the ethics committee and members of the Tizard Centre have reviewed the level of information provided.

Further information:

- Thank you for reading the information about this work.
- You will be given a copy of the information sheet and consent form.
- If you want any extra information, you can call Professor Glynis Murphy (01227 823960) or Mark Brown (07917454573). Or you can write to Professor Murphy at the Tizard Centre, University of Kent, Cornwallis North East, Canterbury, Kent CT2 7NF or to Mark Brown at the Tizard Centre, University of Kent, Cornwallis North East, Canterbury, Kent CT2 7NF.

APPENDIX U

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Study Three School Assent Form

School Number:

Participant Identification Number:

SCHOOL CONSENT FORM FOR RESEARCH

Adapted sex education programmes for teenagers with ASD.

Name of Researchers: Prof Glynis Murphy, Mark Brown

Please tick \checkmark the 'YES' box if you agree. Put an X if you don't agree.

YES

I have had read and understood the information sheet

I have asked any relevant questions I wanted to

I understand that our pupils do not have to take part in the research

I understand that I can pull the pupils out at any time without giving a reason

I understand that all information the pupils provide will be in strict confidence

I understand that some of the assessment interviews will be taped and stored in a secure location

I agree that members of the research team can and may contact me to clarify information provided by pupils.

I understand that members of the research team will feedback the results of the research to me, in writing, upon completion of the research

I agree to take part in the research

Name: _____

Post held: _____

School Name: _____

Date: _____

Signature: _____