

**WHAT ARE THE IMPLICATIONS OF SEXUAL ABUSE WITHIN THE AUTISM  
POPULATION?**

**By**

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## ABSTRACT

The purpose of this research was to examine the experience of sexual abuse through an in-depth phenomenological exploration with autistic survivors. The methodological approach utilised was Interpretative Phenomenological Analysis, considered appropriate for sensitive research. The subject selection for this qualitative research was purposeful and comprised four females and two males with a mean age of twenty-six. They were selected because of their lived experiences of sexual abuse and therefore, they were best suited to inform the research questions. The autistic voice is lacking in research and this study helps to bridge the gap in the literature by gaining the autistic perspective.

The method of data collection comprised six semi-structured interviews which accessed the first-hand voices directly from the individuals. Emotion work theory was utilised to enhance the interpretation of the data, and incorporated the experiences and emotions of both the researcher and the participants. The combination of emotion work and primary data brought to life the 'thinking' and 'feeling' of sexual abuse which is lacking within sensitive research. It added a nuanced and in-depth insight into this much-neglected topic and six superordinate themes emerged. They highlighted the implications and complexities associated with sexual abuse in the autism population.

1. 'The bleeding edge of autistic pain' demonstrated the distress caused by sexual abuse severely impacting upon a survivor's physical and psychological well-being. It brought attention to self-injurious behaviour including suicidal ideation. Participants described aspects of autism that seemed to compound sexual vulnerability.
2. 'My dysfunctional family came at a cost' highlighted the damage caused by living within

this environment whilst considering the disclosure of sexual abuse. 3. 'Autistic chameleon in a crowd' predominantly focused on the dangers associated with autistic camouflaging and people-pleasing. 4. 'Rape culture: The reality beyond the myth' identified that each participant became a victim of rape culture despite controversial perceptions that it is a myth. The participants were sexually vulnerable and experienced the subsets of rape culture which was exacerbated by being autistic. 5. 'Specialist support services: Where are they?' emphasised the lack of specialist support and disjointed support services for autistic survivors of sexual abuse. The participants who accessed inappropriate therapeutic interventions were retraumatised. This highlighted that those positioned to aid the healing process of autistic survivors lacked the appropriate knowledge and skills to effectively support them. 6. 'The importance of sex education for autistic people: The missing pieces?' demonstrated how the participants' experiences added to the knowledge base regarding suitable topics to be included in current sex education programmes to promote healthier decisions, and to aid the sexual safety of the autism population.

This research offers an original contribution to the field of autism and sexual abuse by utilising primary data as opposed to secondary data which may not offer an authentic representation of real-life experiences. Autistic individuals and those who are marginalised and discriminated against are highly susceptible to sexual abuse and violence taking many forms. There is a stark gap in the research addressing this topic, but this study has contributed to knowledge by identifying the implications of the impact of sexual abuse in the autism population. It evidenced that not being in receipt of a childhood autism diagnosis contributed towards the safety, health, well-being, and autistic sexual vulnerability of the participants. A diagnosis at the time of accessing

support services is valuable for practitioners whilst providing specialist therapeutic interventions. The effects of the intersecting taboo of autism, sexual abuse, mental health and post-traumatic stress disorder are missing in the current literature. This research bridges the fundamental gap and recommendations are put forward regarding the implications for policy, practice and support, and future research which are discussed to serve towards the safety needs of those who are all too often silenced.

## **DEDICATION**

Abbi-Sian McAllister

Tragically passed away February 25<sup>th</sup> 2015 aged 23.

I dedicate this work to you Abbi-Sian as you were my main inspiration for this research, and you believed in the importance of giving a voice to autistic people and those with mental health problems.

**COOLIO!**

**X**

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## ABBREVIATIONS

<b>ADHD</b>	- Attention Deficit Hyperactivity Disorder
<b>A&amp;E</b>	- Accident and Emergency
<b>AIDS</b>	- Acquired Immunodeficiency Syndrome
<b>APA</b>	- American Psychiatric Association
<b>AS</b>	- Asperger's Syndrome
<b>ASC</b>	- Autism Spectrum Condition
<b>ASD</b>	- Autism Spectrum Disorder
<b>ATU</b>	- Acute Treatment Unit
<b>BDSM</b>	- Bondage, Discipline, Sadism and Masochism
<b>BPD</b>	- Borderline Personality Disorder
<b>CAMHS</b>	- Child and Adolescent Mental Health Services
<b>CEOP</b>	- Child Exploitation and Online Protection
<b>CJS</b>	- Criminal Justice System
<b>CSA</b>	- Child Sexual Abuse
<b>CTR</b>	- Clinical Treatment Review
<b>DfE</b>	- Department for Education
<b>DoH</b>	- Department of Health
<b>DSM</b>	- Diagnostic Manual
<b>DSM-IV-TR</b>	- Diagnostic and Statistical Manual of Mental Disorders
<b>EBE</b>	- Expert by Experience
<b>EFGT-AS</b>	- Emotion-Focused Group Therapy with Autistic Adolescents
<b>FGM</b>	- Female Genital Mutilation
<b>FTP</b>	- Forced-to-Penetrate
<b>GDPR</b>	- General Data Protection Regulations
<b>GP</b>	- General Practitioner
<b>GT</b>	- Grounded Theory
<b>GUM</b>	- Genitourinary Medicine
<b>HFA</b>	- High Functioning Autism
<b>ICD-10</b>	- International Classification of Diseases and Disorders
<b>IPA</b>	- Interpretative Phenomenological Analysis
<b>ISVA</b>	- Independent Sexual Violence Advisor/Advocate
<b>ITP</b>	- Interpersonal Trauma
<b>LD</b>	- Learning Disability
<b>LEA</b>	- Local Education Authority
<b>LGBTQIA+</b>	- Lesbian, Gay, Bisexual, Transgender, Questioning, Intersex, Asexual
<b>ME</b>	- Myalgic Encephalomyelitis
<b>MEd</b>	- Master of Education
<b>NAS</b>	- National Autistic Society
<b>NHS</b>	- National Health Service
<b>NICE</b>	- National Institute for Health and Clinical Excellence
<b>NSPCC</b>	- National Society for Prevention of Cruelty to Children
<b>OAR</b>	- Organization for Autism Research
<b>OCD</b>	- Obsessive-Compulsive Disorder
<b>PDD</b>	- Pervasive Developmental Disorders
<b>PhD</b>	- Doctor of Philosophy
<b>PLD</b>	- Profound Learning Disability
<b>PTSD</b>	- Post-Traumatic Stress Disorder
<b>RAINN</b>	- Rape, Abuse and Incest National Network

<b>REC</b>	- Research Ethics Committee
<b>SARC</b>	- Sexual Assault Referral Clinic
<b>SAV</b>	- Sexual Abuse/violence
<b>SBS</b>	- Sexual Behaviour Scale
<b>SE</b>	- Sex Education
<b>SGM</b>	- Sexual and Gender Minority
<b>SHC</b>	- Sexual Health Clinic
<b>SLD</b>	- Severe Learning Disability
<b>SPARK</b>	- Speak to the Potential, Ability, and Resilience inside every Kid
<b>SRE</b>	- Sex and Relationship Education
<b>STI</b>	- Sexually Transmitted Infection
<b>TCP</b>	- Treatment Care Plan
<b>UK</b>	- United Kingdom
<b>UNICEF</b>	- United Nations International Children's Emergency Fund
<b>USA</b>	- United States of America
<b>WHO</b>	- World Health Organization

## GLOSSARY AND DEFINITIONS

### Definitions of Key Terms Used in Regard to Sexual Abuse/Violence

**Consent**

Permission for something to happen or agreement to do something

**Date Rape**

Rape by a person with whom the victim has gone on a date

**Disclosure**

The action of making new or secret information known

**Flashback**

A sudden and disturbing vivid memory of a past traumatic event

**Grooming**

Prepare or train someone for a particular purpose or activity

**Healing**

The process of getting beyond trauma. People heal or overcome trauma in different ways and speeds

**Incest**

Sexual assault in which the perpetrator is a parent, sibling, or other family member, relatives, step-parents

**Perpetrator**

A person who carries out a harmful, illegal, or immoral act

**Pornography**

Printed or visual material containing the explicit description or display of sexual organs or activity, intended to stimulate sexual excitement

**Post-Traumatic Stress Disorder**

A condition of persistent mental and emotional stress occurring as a result of injury or severe psychological shock, typically involving disturbance of sleep and constant vivid recall of the experience, with dulled responses to others and to the outside world

**Rape**

Sexual intercourse against an individual's will

**Sexting**

Described as sending text messages, images or videos of a sexual nature via mobile phones or social media sites

**Sexual Abuse**

Used to describe a pattern of sexual violations which often occurs over a period of time

**Sexual Violence**

Defined as a sexual act committed against someone without that person's freely given consent

**Survivor**

A term often used for someone who has been through an experience of sexual assault, dating violence, domestic violence, incest or abuse

**Tonic Immobility**

A common reaction to threatening stimuli which is a freeze response

**Victim**

A term often used for someone who has experienced assault or abuse

## CHAPTER 1

**Content Warning:** This thesis contains graphic detail about sexual violation; self-harm; and suicide which some readers may find distressing.

### INTRODUCTION

#### 1.1 Introducing my thesis

I would like to introduce my thesis with the words of an American psychologist and writer Sandra Scarr, as its meaning is synonymous with my experience of defending the rights of autistic individuals to participate in research that is deemed controversial:

...science is desperately in need of good studies...to inform us what we need to do to help underrepresented people to succeed in this society - unlike the ostrich, we cannot afford to hide our heads for fear of socially uncomfortable discoveries. (Scarr, 1988, p. 56)

The main aim of this study is to gain an understanding of the implications associated with sexual abuse and violence (SAV) within the autism population to help prevent future victimisations. Education is paramount in doing this together with forming connections which is discussed throughout the thesis.

SAV is a universal issue affecting millions of people existing in families of all social, racial, ethnic, religious and economic backgrounds; yet, it is deemed a taboo topic. There has been an upsurge in current social media linking celebrity figures to this crime. High-profile media coverage of celebrity court cases has brought it to the attention of the public. Despite this raised awareness, it seems that society is “burying its head”. Denial is a defence mechanism whereby something may be too painful to

acknowledge, and there can be a refusal to accept its existence. SAV is a violent crime and depending on the jurisdiction can fall within the same category of homicide. Ignoring it will suffice in providing ammunition to those who carry out sexual crimes destroying the lives of innocent people.

## **1.2 Background to autism**

A German psychiatrist Eugen Bleuler, coined the concept of autism in 1911 and described it as a symptom of severe schizophrenia (Evans, 2013). In 1943, Dr Leo Kanner, a child psychiatrist in the United States of America (USA), first introduced the term 'Early Infantile Autism' to explain a type of condition previously unspecified as a clinical entity, although earlier case descriptions can be found. Around the same time in 1944, Dr Hans Asperger, a Viennese paediatrician, published his doctoral thesis and he described a milder form of the diagnosis that became known as Asperger's syndrome (AS) (Attwood, 2002). Arguably, AS is a mild form of autism but for individuals affected by it could potentially be debilitating for them (Jordan, 2011).

Wing and Gould (1979) identified the three main domains in which a person with autistic spectrum disorder (ASD) could present with difficulties and the 'triad of impairments' became the diagnostic tool comprising difficulties in social interaction, communication and imagination. AS is specifically characterised by noticeable and enduring difficulties in social interaction and emotional relatedness, and unusual patterns of circumscribed interests and behavioural eccentricity (Cohen and Volkmar, 1997). Autism and AS were first described and included in the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV-TR) (American Psychiatric Association APA, 2000) and International Classification of Diseases and Disorders

(ICD-10) (World Health Organization WHO, 1993), as two of the five pervasive developmental disorders (PDD) which are often referred to as ASD (Wing, 1997). The APA (2013) has revised its diagnostic manual and although the DSM-5 contains one of the main international sets of diagnostic criteria for autism, the main criteria used in the United Kingdom (UK) at present are the ICD-10 (WHO, 1993).

The previous three domains of impairments have been reduced to two domains: social communication and interaction, and restricted, repetitive patterns of behaviour, interests or activities. DSM-5 includes a new condition called 'social communication disorder'. Although it is not part of the autism spectrum, it is believed that it is likely to be a sub-group of people on the autism spectrum. Additionally, sensory behaviours are included in the criteria under the 'restricted, repetitive patterns of behaviours' descriptors. Including sensory behaviours in the criteria is useful because many autistic people have sensory issues affecting them on a day-to-day basis (Kerns et al., 2022).

The 'triad of impairments' is a description of the way we understand autism to affect an individual. It is important to note that even though the APA (2013) has revised its diagnostic manual, the theory has not changed and people can vary in how these impairments are manifested. It is not expected that there will be any immediate changes to the way autism and AS are diagnosed in this country. They are life-long developmental conditions occurring in varying degrees. They are often referred to as a hidden disability because they may not be immediately visible (Attfield and Morgan, 2007).

### **1.3 Epidemiology**

Autism was regarded as a rare condition for the majority of the twentieth century. It was believed that it only affected a tiny percentage of the population; however, the amount of people diagnosed as autistic or self-identifying has considerably increased within the last two decades (Baird et al., 2006; Bryson, 2003; Chakrabarti and Fombonne, 2005; Fombonne, 2005; Milton, 2019; Parner, Schendel and Thorsen, 2008). This could be due to greater public awareness and previous misdiagnosis (Jordan, 2011), and increased autism awareness associated with other developmental problems (Boucher, 2009). The National Autistic Society (NAS, 2021) acknowledge that there has been a significant increase in the diagnosis of autistic females. The prevalence rates of mental health are higher in autistic people compared to the non-autistic population which may be due to clinicians superseding the mental health needs, and overlooking the symptoms of autism (Gravitz, 2018).

The WHO (2021) estimates that globally one in one hundred and sixty children has ASD but prevalence rates significantly vary within studies and the data suggests that ASD is substantially higher, and in many low and middle-income countries its prevalence remains unknown. Similar to SAV, autism is found in every country and region of the world and in families of all racial, ethnic, religious and economic backgrounds (Barnard, Gerber and McCosker, 2001; Papoudi et al., 2021). However, society is still ill-informed even with the expertise of today's minds (Jordan, 2011; Lawson, 2001; Milton, 2019). Autism influences the way individuals think, feel and experience life, producing outcomes for many resulting in alienation, misunderstanding, depression and suicide (Cassidy et al., 2018; Deudney, 2004; Tantam, 1991).

## **1.4 Reflective journal**

During the research process I kept a reflective journal providing an audit trail of my progress from the start of my study to the final report. It gave me the opportunity to learn more about myself as I engaged in reflective and reflexive thinking which is central to interpretative phenomenological analysis (IPA). I explored personal beliefs, values and attitudes revealing aspects of my life that I had been unaware of. This included my own traumatic experiences which I had not recognised, and it enforced the exploration of my own mental health and coping mechanisms. I felt exposed and vulnerable as I addressed these issues for the first time. The challenges that I had faced shaped me into the person that I am today. This self-awareness was pivotal as it unexpectedly put me in a position similar to my participants and influenced decisions that I made throughout the research. To demonstrate this, I have included extracts from my reflective journal which are presented in reflective boxes. I incorporate annotations of reflexivity within the main body of the study adding to its transparency.

## **1.5 My personal journey of autism**

I developed a keen interest in autism when my son was born in 1991. He received an autism diagnosis and a severe learning disability (SLD) diagnosis seven years later. This was the catalyst which set me on a personal, professional and academic journey of discovering autism. I educated myself about autism and I strongly connected with it. My son's diagnosis was a relief because it enabled the signposting to support services, giving me answers to his seemingly odd behaviour. I was disillusioned by the available literature which portrayed autism negatively and mainly focused on the stigma. My experience of parenting an autistic child and now adult has been rewarding

despite it being emotionally, physically and financially exhausting. Those demands have been intensified by recurrent challenges posed by various sectors consisting of the local education authority (LEA), educators, medical professions, social services, social care and society in general. These fragmentations created a disconnect leaving me confused as to how to effectively support him. The adversity could have been reduced if those involved had the appropriate training and skills to meet our needs. Despite leading a lifestyle that did not fit into societal norms which was compounded by parenting an autistic child, I maintained a positive outlook as I have embraced the identity of my son. I am privileged to have this experience and personal insight into autism which gave me the resilience to carry out this sensitive and much under-researched work.

### **1.6 My professional journey of autism**

My professional experience of working with children and adults with varying levels of autism ranging from profound learning disabilities (PLD) to intellectual archetypes, has spanned over a period of eighteen years. I entered the field of specialist education in 2006 which involved supporting autistic students and their families. This connection gave me a broader depth of knowledge that I had lacked regarding the wider autism spectrum. Whilst the symptoms associated with autism are collective, they can present in various ways and affect individuals differently. They were unrecognised by many educators detrimentally affecting the psychological needs of young individuals. This was the catalyst that drove me towards advocating for the rights of autistic people. In 2011, I entered into higher education providing autism specialist mentoring for students to help to identify and eliminate the barriers to their studies. SAV was an all too common phenomenon and it became a greater area of interest for me. Progression

with my career included working independently and practising outside of the education system. I worked within the National Health Service (NHS) sitting on Clinical Treatment Review (CTR) panels as an Expert by Experience (EBE). This was in line with the NHS England - Transforming Care Provision (TCP) to ensure that the care needs of hospitalised autistic patients were met. It aimed to implement strategies for their reintegration into the community with appropriate support and in close proximity to their home. Investigations into assessment and treatment units (ATUs) and care homes exposes the poor care and treatment of autistic people with mental health problems and/or learning disability (LD). This was highlighted in the Winterbourne View scandal in 2011 whereby patients with LD and/or autism were abused by staff in a private hospital. By switching the system around so that vulnerable people are not hidden away within society, and having open and transparent care and treatment would diminish the opportunity for the abuse of power, and those most vulnerable would be better protected.

Whilst sitting on the CTR panels, patients and parents/carers were given the opportunity to express their views on their treatment whilst hospitalised. Many of the patients had developed post-traumatic stress disorder (PTSD) due to SAV and were hospitalised to treat PTSD. They felt failed by the system because of a lack of autism knowledge and skills by those supporting them. It detrimentally affected their physiological and psychological well-being resulting in limited therapeutic interventions to meet their needs. They felt that their treatment would have been more effective if the professionals had an awareness of autism, and this lack of knowledge created a disconnect with many disengaging from services.

**Reflective box**

My personal and professional perspective has been disappointing regarding the care and treatment of those affected by autism. I have worked in the private and public sectors and they are still facing the same challenges that I did in the early 1990's. Concerningly, over three decades later there is a lack of joined up specialised autism services. I am shocked that in today's modern society that autistic people are institutionalised, and their care and treatment is frequently provided by under-skilled staff lacking autism training/understanding. This is a common occurrence impacting upon the mental health of people experiencing trauma.

**1.7 Rationale**

The foundation of my research originated from my Master of Education (MEd) dissertation in 2013. It explored the experiences of twelve sexually active autistic young adults. A main theme was that the participants lacked appropriate sex education (SE), with implications for their sexual safety. The research identified sex related barriers and sensory sensitivities. The study exposed that the autism population were at a greater risk of SAV than non-autistic people. This prompted me to examine this phenomenon further; however, there was a paucity of literature addressing autism and SAV. This disturbing discovery gave a new impetus to bridge this gap in the literature.

**1.8 Research aim**

The main aim of this study is to gain an understanding of the implications of SAV within the autism population. The objectives are to identify those implications by listening to six autistic survivors. It will be determined through the three R's designed by Haynes (2013) to recognise, report and aid the recovery of SAV within the autism population:

1. **Recognise** the signs/behaviours of autistic individuals who have experienced SAV to raise awareness for parents/carers and professionals enabling them to

meet their needs within their supportive role, and to examine why autistic people are vulnerable to SAV.

2. **Report** SAV in the most effective way and examine how survivors are treated, supported, and communicated with upon disclosure.
3. **Recovery** of SAV is possible but the process may be different for each person, and it will be useful to determine the experiences of each individual's recovery.

The experiences of autistic individuals are lacking in many studies. It is only from their perspective that we can begin to understand the implications associated with SAV. Societal attitudes can inhibit research on sensitive issues but addressing them will help to eliminate the stigma associated with SAV. Hopefully, the current research will serve towards eradicating the stigma and to achieve this, the following research questions were examined:

1. How do autistic individuals make sense of their lived experiences of SAV?
2. How does being autistic increase sexual vulnerability?
3. What are the implications for policy, practice and support?

### **1.9 Preparatory work**

#### **Reflective box**

I was at an advantage regarding the preparatory work for this research as I had a clear idea of the research question at the outset. This is contrary to many doctoral students who have difficulty in identifying a suitable topic within the preliminary stages of their study. Taking early ownership enabled me to be forward thinking regarding the depth of preparatory work required to meet the needs of vulnerable participants who were prepared to discuss their experiences of SAV. It was essential that I was thoroughly well-versed on the subject to gain the understanding required to effectively interview them. I reviewed horrific accounts of SAV as I needed to be prepared to hear similar stories during the interviews. It was a disturbing read and some of the stories seemed too horrifying to be true. Despite the distressing content I did not emotionally respond. The accounts lacked compassion and a sense of

reality, and the literature did not do them justice. I then discovered the work of Rebecca Campbell, a researcher who studies rape. She incorporates her own emotionality into the research process enabling the 'thinking' and 'feeling' of rape and this is discussed in chapter 3.

Extensive preparatory work was carried out ensuring the safety of *all* involved in the research process as it focused on socially sensitive issues that are associated with stigma and taboo. I complied with exhaustive ethical procedures which are discussed in chapter 3. The preparatory work was intensive, particularly as there was ambiguity within the literature defining 'vulnerable participants' and 'sensitive research' which was central to the study. All aspects of this research were multifaceted regarding the intersect of autism; sex; disability; SAV; and PTSD. These ingredients made a recipe for a phenomenon deemed taboo and interrelated with social stigma. This was a complex undertaking accompanied with significant responsibility regarding the psychological and physiological needs of *all* involved. Stringent safety protocols were established to identify and minimise risk throughout the research. Although the existing literature offered general guidelines concerning the safety of vulnerable participants, there was a lack of consideration given to the protection of the researcher. I was inspired by the work of Campbell (2002), Dickson-Swift et al. (2007), and Barnard, Gerber and McCosker (2001) as they recognised the importance of researcher emotionality within the field. They examined how researchers were affected by their emotions whilst undertaking sensitive research, and how emotions influenced the research findings. It highlighted the limited literature in the field and recommended further work of 'researching-the-researcher'. They exposed the psychological, physiological and emotional risk factors of everyone involved in the process. They recommended that safety protocols need to be implemented at the outset of the research addressing any risk factors that may emerge. They pointed out

the necessity to undertake sensitive research in a supportive environment ensuring the safety needs of all involved. Fenge et al. (2019) highlight the gap in research concerning the emotions of the researcher and addressed the effects of disturbing data that they work with. The study identified how researchers were affected by emotionality whilst undertaking sensitive research and the demands they met regarding positionality whilst working with marginalised voices (Fenge et al., 2019). Two fundamental themes that emerged were 'researcher positionality' and 'preparedness'.

The emotions of researching emotionally difficult topics are often overlooked in academic discourse. Yet, the emotionally engaged researcher bears witness to the pain, suffering, humiliation, and indignity of others over and over again. (Campbell, 2002, p. 150)

There has been an increase in the area of 'researching-the-researcher' whilst undertaking sensitive research (Carpenter, 2015; Dickson-Swift et al., 2007; Fenge et al. 2019; Pezalla, Pettigrew and Miller-Day, 2012). It is essential to build upon this neglected area to ensure the psychological and physiological needs of the research team are met. Dickson-Swift et al. (2007) highlight the importance of the psychological well-being of researchers and that emotionality work is undervalued within the university culture. They advocate for informal and professional support to improve their well-being. Researcher safety is an integral part of sensitive research. There is a demand for enhanced understanding of how researchers are impacted whilst immersed in emotion-laden topics. It would be valuable to utilise the personal experiences of those who have undertaken sensitive research to inform the research evidence.

I considered my positionality at the outset of this research but I did not initially consider my psychological and physiological safety needs. As a novice researcher, my initial concerns were how I would react to the narratives during the interviews as inevitably it would be distressing. Experienced researchers are not exempt from the effects of disturbing data and their psychological and physiological needs have been overlooked within the social sciences (Campbell, 2002; Fenge et al., 2019). I considered the implications of being immersed in emotion-laden data for several years starting at the proposal stage to the final report.

I did not expect that undertaking this research would be an easy feat, particularly as I was positioned as the researcher, interviewer, transcriber and analyst. Researcher preparedness was vital to meet my safety needs and those of the participants. Fenge et al. (2019) state that some topics may be unsuitable for some researchers and recommend self-reflection to ensure that they are able to undertake the research. I felt that I was able to conduct this research despite its complexity because of my commitment to the safety of the autism population. I engaged with reflexivity and reflection work which was core to establishing that my mental health was sound. Poor researcher well-being can detrimentally affect the safety of participants (Moncur, 2013). I reflected upon my personal traits and discussed them with close family members, friends and colleagues. They agreed that I was mentally in a good place to undertake this research. It was thought-provoking as it was a reminder of my personal experiences of trauma. I recalled the impact that it had on my mental health at that time and the high level of emotional resilience to overcome it. I was satisfied that I had the mental hardiness which would stand me in good stead for undertaking complex and sensitive research.

### **1.10 Use of autistic terminology**

Various terms describe autism and in recent years there has been a shift in the terminology used. The power of language used shapes a person's perception of autism (Kenny et al., 2015). The Department of Health (DoH, 2010) referred to it as an autism spectrum condition (ASC) because of the range of difficulties affecting autistic adults, and the presentation in different people. The use of terminology may be controversial whilst labelling an autistic individual, particularly when medical terms are used including deficits or disorders as they are associated with stigma (Milton, 2019). This can be considered offensive within the autistic community, especially for those embracing their autistic identity. Some individuals feel that it cannot be separated as it is an integral part of their authenticity (Milton, 2012). Throughout this thesis and in line with autistic self-advocates, I will not refer to 'people with autism' but 'autistic people' (Milton, 2012). It is important to note that the participants in this research received an autism diagnosis in adulthood. Although they did not use identity-first language, I did use it because it is beginning to be supported by autistic people and their families that embrace their identity (Taboas, Doepke and Zimmerman, 2023). I felt this language was in keeping with the way the participants in this research expressed their autistic identities and embraced diagnosis. Whilst making references to quotations or citing books or research papers, certain terminology regarding how autism is addressed will be unavoidable.

### **1.11 Hearing the voice of autistic individuals**

I have struggled to understand why autistic voices are seldom heard in general and within research. I have included autistic people in previous studies and their contribution was invaluable. Milton (2014) advocates the slogan: 'Nothing about us, without us' giving attention to autistic people who are frequently denied the decisions impacting upon their lives. Autistic individuals can be discriminated against and under-represented within a society which frequently treats them unfairly, and they are regularly left to go unnoticed and unheard. Autism can be perceived as a stigma, and this is not helped by the way it is portrayed in the literature which tends to focus on the negativity rather than the achievements. To get a balanced perspective regarding negative and positive attributions, it would be valuable to listen to the voices of autistic people who share their accomplishments. MacLeod (2016) undertook a study giving a voice to sixteen autistic students to share their lived experiences of success. The findings elucidated the need for autistic people to make themselves 'extra-visible' regarding the way society perceives their failures compared to their successes. Whilst autism is typically referred to as a hidden disability, autistic people are not invisible and they have much to offer. If we do not give them a voice and listen to what they have to say, society could be missing out on international influencers like Greta Thunberg an environmental activist. She presented a TED Talk and explained:

I was diagnosed with Asperger's syndrome, OCD and selective mutism. That basically means I only speak when I think it's necessary. Now is one of those moments. (Thunberg, 2018)

Thunberg (2019) states that for all of her life she has been invisible and faded into the background feeling unseen and unheard. However, she made herself visible and became well-known internationally for her participation in a major climate protest in history. Her voice was loud and clear as she gave powerful messages about an

existential emergency that faced humanity due to climate change. I have been inspired by listening to the voices of autistic people including Dean Beadle; Ros Blackburn; Wenn Lawson; and Damian Milton. I have read many autobiographical accounts (Williams, 1996; Holliday Willey, 1999; 2003; King, 2012; Grandin, 1996). Whilst learning about their experiences, it gave me a deeper connection with autism and how autistic people viewed the world from a different perspective.

My close engagement with autistic individuals has enabled me to be privy to personal insights that many people have not had the privilege to witness. This awareness was influential regarding the way I worked and connected with autistic people. I have aspired to encourage them to have their voices heard to educate others. Just as autistic people learn from non-autistic people, it is just as important that non-autistic people learn from autistic people. A common response was that they did not believe that voicing their experiences would be of interest to others. It was saddening that from their perspective they held little or no value of themselves, and poignant regarding them being the most interesting people that I have met. They have given me much autism knowledge and introduced me to worldwide issues that I had previously been disconnected to. By taking an interest in autistic people and allowing them to speak out can help to maximise their own sense of autonomy. During my work as a mentor, I have enlightened autistic people about the inspiration I have gleaned from listening to autistic voices and how it influenced my understanding and teaching of autism. This resonated with them and it encouraged them to find a way of effectively voicing themselves. Connecting with their favourite pastimes including fine art, drama, poetry, sculpture, creative writing, film and various creative channels enabled them to express their voice, reporting that it empowered them. Educators informed them that their

communication style gave them a better understanding of autism which resulted in them making a connection. This improved their education because they felt understood by their educators, and in some cases the educators changed their way of teaching to meet the needs of autistic students.

Milton (2014) states that autonomy is important for the well-being of autistic individuals. To effectively express oneself is a contributing factor regarding safety, particularly when confronted by potentially harmful situations relating to one's physiological and psychological well-being. Creativity can add value to the quality of life for autistic people promoting a healthier way of living. Arguably, it is more important for autistic people to be given a voice because of their vulnerability compared to non-autistic individuals. Nevertheless, as a non-autistic person, I struggled to have my voice heard for many years whilst advocating for my son in an attempt to gain his autism diagnosis.

**Reflective box**

I do not have a disability yet I struggled for many years to have my voice heard. It had a damaging impact on my physiological and psychological well-being. It was a big ask of autistic people to lay bare their intimate details, and I questioned how much I would expose of myself for research purposes. I considered the benefits of being given a voice. It struck a chord as I reflected upon the years that I had desperately wanted to be listened to in the midst of my helplessness as a new mother parenting a child with behaviour that challenged me, and at times to the extreme. I was overjoyed at the prospect of becoming a first-time mother and I visualised a happy future whilst embarking upon family life. I had a healthy pregnancy and a straightforward birth and welcomed a baby boy into the world. Unexpectedly, immediately after his birth I was informed that he had characteristics that did not fit into the norm, and a chromosomal abnormality remaining undiagnosed. I was thrown into unknown territory - "the medical profession". This was the beginning of years of hospital visits, and frustrations at having to repeat myself countless times to paediatricians, consultants, geneticists, neurologists, psychologists, doctors, health and social care workers; the list goes on. Despite undergoing medical assessments, examinations, reviews, observations, scans, educational assessments and many more than I care to remember, I was continuously told that he only had a slight developmental delay. Even as a new mother, I knew that there was something different about my child as he did not typically respond in the same way as other children. When he was eighteen months

old, my motherly instincts told me that he was autistic. I tried to discuss this with the health professionals but I was not listened to. I repeatedly tried to voice my concerns but I was told that I was over-protective, paranoid, exaggerating, catastrophising, *not in control* of his behaviour; simply put, I was disbelieved. Who was I to argue with medical professionals? I was just a mum. What did I know? I had not experienced personal trauma until then, and I did not recognise it as any big deal. It was only when I engaged in reflexivity for this research and reflected upon my personal traits, that I realised that I had been through a physiological response to trauma and it was a somatic experience. Parenting an autistic child can be traumatic, especially with the added challenges of fighting for a diagnosis and then to be struck with unexpected medical problems including his major heart surgery. After battling for what seemed a lifetime, my voice was finally heard on that near fatal day when he accidentally set fire to our home, with his three younger siblings asleep. The fire-alarm startled me. I woke up to the smell of smoke. As I ran downstairs I had many thoughts racing around in my head. The kitchen door was closed, black smoke seeping beneath it. I dreaded opening it. I did not know what to expect or the level of destruction that I would be faced with. My heart was in my mouth. I was highly strung and I thrust open the door. To my astonishment my son was standing there, *safe*, barely scathed by the fire. I was so relieved. Despite this relief, it felt surreal. It was eerie. This beautiful blue-eyed blonde-haired little boy that looked angelic was laughing, *hysterically*. It almost felt evil, why would he do this? We could have been burned to death. But, how was he to know the danger of what he had exposed us to? It was not intentional... but, why? How was I to know that he had created a calming environment in his world, feeling safe from the chaos and unpredictability of a non-autistic world. He was simply getting pleasure from the sensory stimuli generated from the fire, flames, patterns, pretty colours, smell, warmth, which was relaxing and mesmerising. How was he to know it was a mode of destruction? That was the catalyst to my voice being heard, loud and forthright. My frustration intensified in the consultation with the paediatrician. He said “this is serious” and I replied “I know. I have tried to tell you many times about his behaviour and I have been ignored”. I smile when I remember his reply “but, you always seemed calm and coped so well”. Yes, that was my coping strategy, just get on with it because nobody listens anyway. Disturbingly, it took a potentially life-threatening event to be listened to. An urgent referral was made and a diagnosis of autism and SLD was confirmed. I do not like the term “I told you so” - but, “mum knows best!”

I hope the above reflection has highlighted the relevance of listening to individuals to support their needs. The following illuminates the importance of what we can learn from disabled people.

### **1.12 Eva Kittay: Mother knows best - Learning from my daughter**

I was drawn towards Eva Kittay, an American philosopher and feminist activist, because of her strong conviction towards disability studies. They were enhanced by her personal experiences of parenting a daughter born with cerebral palsy and a profound cognitive disability. Despite it being a life-changing experience, Kittay embraced her child's identity informing her philosophical understanding of disability. She brought to life the challenges of parenting a disabled child and the ethics of care that came with it. She embraced the rewards that she experienced and the intellect gained from her connection to disability. As a philosopher and a mother, Kittay advocated on behalf of her daughter as an equal within society. She strived to fill the void in the literature portraying disability in a negative light and emphasised the importance for the inclusivity of disabled people. Kittay (2008) welcomes the diversity of bodies and minds and those diverging from the norm to educate and enrich society. As a fervent supporter for the equality of rights between disabled and non-disabled people, Kittay is one of a few feminist philosophers who introduced her experiences into the literature. As a philosopher and educator, she endeavoured to challenge the criticisms of those classifying people with disabilities as less than human (Kittay, 2008).

### **1.13 Human after all: Definition of human: A person**

I have not found a definition in the literature portraying a person as a lesser human being because of their disability whether it is physical and/or intellectual. The dehumanisation of disabled people creates a disconnect manifesting prejudice and stigma which can negatively impact upon lives. This is concerning, particularly as disabled people make up over 10% of the population equating to approximately six

hundred and fifty million people (WHO, 2011). It is only by bringing these issues to the forefront of the public domain that we can begin to eradicate preconceived opinions dehumanising millions of people. This is discriminatory and I can offer an authentic reflection of what we can learn from our disabled children.

### **1.14 Learning from my son**

I was fortunate to be gifted with an autistic child and have the chance to learn from the challenges and rewards that he presented. I would not have entered the world of academia without this experience. He connected me to autism which set me on an intellectual journey and I do not envisage that this will change in the foreseeable future. Many academics may have had this unique lived experience but there appear to be limited contributors within the field. This is a fundamental loss concerning the knowledge that they could share adding to the research evidence because lived experiences are invaluable. Although they cannot be fully captured within the literature alone arguably, introducing personal experiences into research could suffice in linking theory to practice to present real-life situations as a resource for knowledge. Withholding my personal experiences within the research process would not give justice to my son regarding what he has unwittingly taught me, not only about autism but myself. I would be doing myself a disservice if I did not share the knowledge gained from my experiences which have not been in vain, and I hope others will learn from them too. The following reflection offers a brief synopsis of my initial ignorance regarding disability and how my increased knowledge of disability fundamentally deepened my understanding of diversity.

#### **Reflective box**

When people realise that my son is autistic, it seems to create an air of awkwardness, not on my part, but theirs. Subsequently, a familiar pattern follows

and they remark “*I am sorry*” in the same way you say sorry to hear about someone’s loss. I then say “why are you sorry?” Then they apologise, and I explain that they do not need to be apologetic. Simply put, I guess it is ignorance and not understanding the diversities in life. My son has faced many difficulties during his thirty-three years and I do not envisage this changing. However, he leads a rewarding and fulfilling life as do my non-autistic children, just in different ways. Mother nature works in mysterious ways and I never expected to parent a disabled child, that sort of thing happened to other people. How naïve, well yes, I probably was when I was twenty-four and thinking I knew it all. Retrospectively, *what did I know?* I knew nothing about disability, diversity, inclusivity, and autism was a *word* that I had once heard of. Until the birth of my son I had led a shallow existence, but how my son has changed that. He enriched my life to the point that I never thought possible and taught me “the meaning of *my* life”. It is not so much the challenges that we face in life but the way we manage, learn, and grow from them. The challenges shape us into the people that we become adding to our own beliefs and values. I would not want to change what I have been given, so do not be sorry for something perceived as lesser value because it does not fit into societal norms. Do not apologise for your ignorance either, because I lead a life that is filled with depth which many people would not dare to look into for fear of what they might see and learn.

### **1.15 Summary**

The topics discussed in this chapter informed my rationale for this research. My personal and professional experiences elucidate the importance of undertaking complex and sensitive research to raise awareness of SAV within a populace deemed vulnerable. My dedication to the topic being discussed underpinned the necessity for this study to be conducted to provide an insight into the implications of autistic SAV to fill the gaps in the research evidence. My lived experience of parenting an autistic child/adult has been emotionally and physically exhausting but it has also been a positive experience which has served many purposes. It connected me with the autism population, and I was introduced to the wider autism spectrum. I have engaged with the challenges and positive outcomes experienced by diverse populations and it instils faith that from the depths of despair, there is hope. This was the catalyst that gave me the yearning to give autonomy to marginalised individuals, and to those who have a voice which frequently goes unheard. Immersing myself into research deemed taboo

has afforded a nuanced understanding into an under-researched phenomenon. Open discourse is a significant starting point to eradicating the stigma associated with SAV in general. Equally, frank discussion regarding the autism population is vital due to their high susceptibility to SAV. Acknowledging and discussing topics that are taboo can help to remove the veils of secrecy. It can expose and minimise stigmatising perspectives that are deep-rooted within a society that is frequently fearful of the realities of 'thinking' and 'feeling' SAV. It potentially makes it easier for other survivors to feel that they can make a disclosure in order to receive help and understanding.

### **1.16 Outline of thesis**

Chapter two details the identification of the relevant literature regarding the implications of SAV within the autistic population. A systematic approach was applied to elucidate literature from the academic and grey literature, and autistic bloggers who had survived SAV. In chapter three I discuss the methodological process to effectively answer the research questions. It informs the reader of the rationale for IPA and identifies the key theoretical underpinnings of the methods utilised within this research. I incorporate a comprehensive account of my positionality. Ethical considerations for undertaking sensitive research with vulnerable participants are discussed. I offer a brief description of each of the participants to enable the reader an insight into their lived experiences. Chapter four gives a detailed narrative of the superordinate and related subordinate themes which emerged from the voice of six autistic survivors of SAV. Finally, in chapter five I conclude my research findings regarding the current literature within the field of SAV. It affords the limitations and recommendations for policy, practice and support, and future research.

## **CHAPTER 2**

### **THE LIVED EXPERIENCE OF SEXUAL ABUSE AND VIOLENCE, AND AUTISM: REVIEW OF THE LITERATURE**

#### **2.1 Introduction**

To identify literature concerning the implications of SAV within the autism population, I undertook a systematic approach utilising EBSCO Databases and ProQuest Social Sciences databases. Within the databases I used Boolean search using the parameters of “autism” and “sexual abuse” to obtain publications. The search was initially limited to peer-reviewed journal articles spanning the previous five years from 2018 to 2023. Due to the limited literature available, I extended the search to include publications from 2013 to 2023. The first search was conducted in January 2023 and repeated in July 2023 to identify the latest publications.

The literature provides evidence that the autistic population are highly susceptible to SAV compared to non-autistic people, but first-hand accounts by autistic individuals themselves are lacking in published research. To bridge this gap, I searched the grey literature utilising a different approach to the main academic literature review. In providing a framework for the search strategy, I utilised a systematic search using customised Google search engines. Grey literature is frequently found on the internet as it is a platform used to contribute to creative sources of data (Godin et al., 2015). The inclusion of grey literature reflects a diverse and heterogeneous body of material outside of conventional academic peer-review processes (Adams, Smart and Huff, 2017). The application of systematic methods to grey literature searches enhances

the calibre of review syntheses whereby grey literature is included because comprehensive information can be examined with less bias (Godin et al., 2015).

In contrast to the published literature, the Google search accrued a vast amount of information spanning across a broad range of topics. Concurrently, additional publications were located pertinent to this research. To limit the literature, I considered the areas of interest that were of relevance. The purpose of this study was to engage with the reality-phenomenon of individuals' lived experiences, and to examine how they made sense of it from their unique perspective. I excluded government documents and/or reports; marketing reports; policies; surveys; and statistical reports. I eliminated articles from organisations and those that did not reference autism and SAV because it was important to capture the first-hand accounts of autistic individuals. Therefore, I only explored the SAV experiences of autistic bloggers and below are the inclusion criteria:

- Accredited blog article sites for data collection
- Male and female adult autistic survivors of SAV within the UK, and globally
- Ability to effectively communicate their lived experiences in spoken English.

I limited the search from the timeline of 2018 to 2023 producing up-to-date and novel data ensuring currency. I combined the search terms which were “autistic bloggers”, “autism”, “sexual abuse and violence”, “PTSD”, and “phenomenology”. The Google search supplied blog articles on sites such as Respond and NeuroClastic. It was essential to exercise caution whilst reviewing the blogs but I was confident that the sites were credible and produced data that was authentic. This was substantiated as Respond is a national charity supporting people with LDs and autism, providing

specialist therapeutic support to those who have experienced SAV and trauma. Furthermore, NeuroClastic publishes information from autistic individuals themselves, and material relating to the autism spectrum. Subsequently, I limited my search to these particular sites as I chose quality over quantity enabling a more in-depth and credible understanding of the phenomenon under discussion.

The sites provided distinct voices from varied writers and organisations bringing to life the stark realities of SAV which was limited in the main review. This afforded fascinating first-hand accounts from autistic individuals. Publications and blogs were utilised from the grey literature to support the published literature. Although the autistic voice was largely absent from the empirical literature, it was evidenced in the grey literature validating the experiences of SAV. Acquiring knowledge from autistic individuals themselves substantiates the realities they experienced surviving the aftermath of SAV. This primary data is valuable because it reflects authenticity evoking the emotionality of SAV that is missing within the published literature.

I selected five bloggers because they provided valuable accounts that were relevant to this research, and they shared their experiences to the public at large. Some blogs produce data that are "...highly confessional and self-analytical blogs whereby bloggers make sense of their identity and relationships with others" (Hookway, 2008, p. 102). The bloggers were in dialogue with each other thus commenting on individual posts. They effectively communicated their experiences via writing and as they spoke explicitly about their intimate experiences, it brought to life the 'thinking' and 'feeling' of SAV which was missing in the academic literature. The bloggers explained their reasoning for posting their stories, and it was to have their voices heard to raise

awareness of SAV within the autism population. This supports my rationale for this area of research.

The literature review covers a brief overview of SAV within the general population, but primarily it affords a detailed review from the autism populace to gain a better understanding of the implications of SAV from their perspective. This is not intended to be comparative research between autistic and non-autistic survivors of SAV, but similarities and differences are discussed. It draws upon the autistic voice and the grey literature engages with autistic bloggers who have the lived experiences of SAV, adding to the gap in the empirical literature. SAV from first-hand accounts of late diagnosed autistic survivors is discussed. Autistic sexual vulnerability is covered which is limited within the published literature but is found in the grey literature. It incorporates gender diversity and sexual identities highlighting the adversities faced by marginalised groups, particularly when autism is added to the mix. The literature also draws upon the barriers to disclosing SAV and the challenges faced by autistic survivors of SAV, and secondary victimisation is also incorporated. It covers the implications of the convergence of autism; SAV; mental health; trauma and PTSD; in addition to the literature on mental health and autism generally. It addresses the lack of autism awareness of healthcare professionals and the impact of ineffective therapeutic interventions. Finally, the importance of SE is considered and highlights the lack of effective programmes to meet the needs of autistic individuals.

The research evidence regarding SAV is generally gained via second-and-third-party sources such as online surveys, questionnaires and secondary data. Police reports, clinical settings studies and non-governmental organisations are another means of obtaining data. Predominantly studies have drawn upon reports from a parent and not

from the child victim (Gibbs et al., 2021; Gibbs, Hudson and Pellicano, 2022). Although secondary data is informative it does not capture the reality-phenomenon of the survivor. This could skew the research evidence as it does not offer a true and nuanced reflection from the individual's perspective. Adding to the secondary evidence base would be valuable to obtain first-hand knowledge of the experiences of survivors of SAV but the current literature is deficient.

I have presented the academic and grey literature using a thematic approach. This is recommended whilst undertaking qualitative research because of its flexibility which permits the researcher to ascertain themes in various ways whilst ensuring consistency (Braun and Clarke, 2006). I identified important themes and patterns which were of interest, and relevant in addressing the research topic under discussion (Maguire and Delahunt, 2017). This was beneficial because it highlighted the current gaps in the published literature.

## **2.2 A brief overview of sexual abuse and violence within the general population**

The purpose of this literature review is to critically evaluate the existing published work and grey literature regarding SAV. The available literature is representative of the general population which is significant, but the intention is to elicit information about the lived experiences of autistic survivors of SAV. The literature review identifies the gaps in knowledge concerning the implications of SAV within a populace deemed vulnerable and marginalised in a society that is all too frequently, ableist. A greater insight will help to strengthen the knowledge base in this under-researched topic and serve towards suitable and effective support. The literature review revealed the vast amount of literature concerning SAV within the general population who are highly

susceptible to SAV (Sardinha et al., 2022). It is one of the most damaging crimes that can be inflicted upon a person (Kruttschnitt, Kalsbeek and House, 2014). In England and Wales, Rape Crisis (2022) reported a 32% increase in the number of recorded sexual offenses against children in the UK over the last year in the general population. One in six children have been sexually abused, and in adulthood one in four women and one in twenty men have experienced SAV (Rape Crisis, 2023). Manukrishnan and Bhagabati (2023) state that in India more than 53% of children have been sexually violated and 52% were male and 48% were female.

A common theme to emerge from the research evidence was SAV in women. Laskey, Bates and Taylor (2019) claim that there is an ample supply of research evidence highlighting female SAV. It is a trauma affecting millions of females and can have long-lasting harmful effects on their well-being (McMahon and Seabrook, 2020). Schiewe (2019) acknowledges that historically women have been subjected to SAV in various settings, and states that it is an epidemic. It is reported that five in six rapes of women was by someone they knew (Rape Crisis, 2023). Despite the myths associated with strangers being the perpetrators of SAV, it is more common for an individual to know their abuser (Manukrishnan and Bhagabati, 2023). Despite society striving towards being safe and violence free, men and women have normalised SAV faced by women (Metz, Myers and Wallace, 2021).

According to McDonald and Tijerino (2013) the majority of SAV victims are female. Although the data indicate that females are more susceptible than males, these figures may show an untrue reflection on the reality of male victimisation due to reporting bias.

Males too can be exposed to SAV but it is a topic that is not well addressed in the academic literature compared to females (Javaid, 2016; Widanaralalage et al., 2022). The literature review identified a gap within research highlighting a lack of studies addressing the victimisation imposed upon males compared to female SAV, and it emerged as a common theme. Autistic bloggers aspiewolf (2019) and Mark Kent (2019) acknowledged male SAV. Aspiewolf indicated that it is common and boys can experience it recurrently. He felt shame that someone was able to do it to him suggesting self-blame. Males experience the same effects of SAV as women but there appears to be a greater stigma and taboo associated with men. Male abusers of other men are likely to get away with it safe in the knowledge that they will not be reported to the criminal justice system (CJS) due to the victim's sexuality being questioned (Hine, Bates and Wallace, 2022). A broad body of research from various disciplines examines the criminal and civil justice system responses, impacts and treatment for females (McDonald and Tijerino, 2013). However, a change is needed in the UK's CJS enabling men to gain justice whilst surviving perpetration by females, and it is also a universal issue. It would be useful to see more empirical research highlighting the prevalence rates in men compared to women. However, the Rape, Abuse and Incest National Network (RAINN, 2022) suggest that this would be a difficult undertaking due to SAV being one of the highest crimes that goes unreported.

An important theme to emerge from the published literature was rape culture which is a widespread issue. Survivors are not immune to it despite differences in cultures, ethnicities, faiths, ages, sexualities and disabilities. The subsets of rape culture include domination; loss of empowerment and control; sexual objectification; normalisation of SAV; and disbelief upon disclosure. Based on recent public platforms which are rife

with accounts of survivors' experiences of SAV, rape culture exposes several issues including consent; proving resistance; victim-blaming; inequity of justice for the victim; perpetrator exoneration; and a lack of understanding concerning tonic immobility which is when a victim freezes during violation (Schiewe, 2019). There are widespread myths about rape creating the basis for a rape culture justifying SAV whereby the victims are blamed and the perpetrators are excused (Urban and Pyland, 2022).

Controversially, Luke Gittos, a solicitor who defends allegations of rape and SAV and a legal editor for Spiked online, titled his book: *Why rape culture is a dangerous myth. From Steubenville to Ched Evans* (2015). A convincing counterargument in response to his perception that rape culture is a myth was forwarded by Professor Johanna Stiebert, a German New Zealander university teacher. She believes that Gittos dismisses the reality of rape culture undermining the testimonies of those who come forward. She acknowledges that he deems rape to be a terrible crime but states: "He may deny the existence of rape culture, but his book betrays the fact that he is there, right in its midst" (Stiebert, 2018, p. 15). I agree with her viewpoint as she takes aim at Gittos's perception that if rape culture existed, it is a phenomenon that is highly sensationalised to create a toxic ideology (Stiebert, 2018). She names other prominent figures who share the same viewpoint as Gittos. Whilst there is scepticism that rape culture does not exist, the literature exposes that it is a reality.

### **2.3 Characteristics of individuals who are vulnerable in the general population**

Several studies have addressed the characteristics of vulnerability in individuals and its effects on a survivor of SAV (Bach et al., 2021; Basile and Smith, 2011; Clarke et

al., 2023). However, the literature review identified a gap in the empirical research addressing the survivor voice whilst accessing effective support. The notion of vulnerability applies to individuals who are heightened to the exposure of risks compared to their counterparts, and that its degree and type varies between countries (Arora et al., 2015).

Being vulnerable is defined as in need of special care, support, or protection because of age, disability, risk of abuse or neglect. (Gov.UK, 2022). (no pagination)

Vulnerable people are highly susceptible to poor physical and social health and more likely to get a disease or illness (Rukmana, 2014). A study undertaken by Numans et al. (2021) comprised thirty-three in-depth interviews including sixteen purportedly vulnerable people, exploring their concept of vulnerability. The findings revealed that psychological, physical and financial vulnerability were the three main types and they are often combined (Numans et al., 2021). Clark and Preto (2018) specify that vulnerability is not necessarily a negative attribute: “To be human is to be vulnerable” (no pagination), but we still remain obligated in addressing vulnerability. There is a growth in adults that are at risk of harm, and in the UK important cases have been brought to national attention such as the Winterbourne scandal (Boland, Burnage and Scott, 2014) that I mentioned previously. The National Society for Mentally Handicapped Children and Adults (MENCAP, 2022) state that it is essential to protect vulnerable individuals from exploitation because they might be unable to keep themselves safe. It is likely that they have little ability to foresee and refrain from danger, and may be unable to recover (Rukmana, 2014).

## **2.4 Impact of sexual abuse on the life of a survivor**

The grey and published literature evidenced the heinous crime of SAV and the implications it has for survivors. Vera-Gray (2023) advocates for the importance of understanding intersectionality whilst considering the impact of child sexual abuse (CSA) which may be affected by factors comprising the sex of the survivor; culture; ethnicity; disability; sexual orientation; and gender identity. SAV impacts upon survivors differently and the effects may last either a few days or many years, or they might not particularly be affected by their experiences (Rape Crisis, 2024). Similar patterns emerged regarding the impact it has upon the lives and well-being of survivors which may include some or all of the following: psychological, emotional and physical effects; depression; anxiety; flashbacks; PTSD; self-harm; sexually transmitted infections (STIs); substance abuse; dissociation; panic attacks; eating and/or sleep disorders; pregnancy; and suicidal ideation (Kruttschnitt, Kalsbeek and House, 2014; RAINN, 2022; 2024). Manukrishnan and Bhagabati (2023) highlight that SAV adversely impacts upon a survivor's self-esteem; interpersonal relationships; social life; sexual functioning; and it may negatively affect their mental health. The literature identifies key barriers attributed to implications with the crime including embarrassment, shame, guilt, stigmatisation or being disbelieved (McElvaney et al., 2021). Sadness and hopelessness can be associated with the aftermath of SAV (Kildahl et al., 2020), and also anger, fear, frustration, sexual intimacy or no emotions at all (Lawson, 1998; 2005).

### **2.5 Effective support that survivors of sexual abuse and violence would benefit from**

There is a plentiful supply of guidance from various voluntary organisations that treat survivors of SAV comprising Women's Aid; Victim Support; Rape Crisis England and

Wales; National Society for the Prevention of Cruelty to Children (NSPCC); Samaritans; Male Survivors Partnership; to name a few. Support can be provided by a general practitioner (GP); sexual assault referral clinic (SARC); hospital accident and emergency (A&E) departments; a genitourinary medicine (GUM) or sexual health clinic (SHC); and counselling services. Although SAV is rife, there is a lack of the survivor's voice in the empirical research. Surprisingly, I was unable to find research evidence examining first-hand accounts of the specific support needs of survivors of SAV. Vera-Gray (2023) believes that survivors are their own best experts on the effects of SAV; therefore, understanding the impacts on an individual should start with them. Hearing the voice of survivors and what they deem appropriate support would be valuable in understanding effective treatments to aid recovery.

## **2.6 Sexual abuse and violence within the autism population**

A common theme to emerge from the literature was that the autistic population are more highly susceptible to SAV compared to non-autistic people (Gibbs, Hudson and Pellicano, 2023). The literature review elucidated the large amount of SAV literature generally, albeit first-hand accounts were missing. Contrastingly, there were far fewer studies concerning the autistic populace. There is an immense amount of research on CSA but it is a much-neglected area for child victims with neurodevelopment problems (Carbajal and Praetorius, 2020). The United Nations International Children's Emergency Fund (UNICEF, 2021) acknowledge that it is difficult to compare research and estimate the prevalence of SAV of disabled children regarding the various ways that countries delineate and gather data from the victim. Studies undertaken into CSA with various disabilities have been consistent within their findings, identifying that

disabled children are at a greater risk than those without a disability (Åker and Johnson, 2020; Christoffersen, 2022; Weiss and Fardella, 2018).

The studies examining the extent of SAV within the autism population have predominantly utilised secondary sources including surveys, questionnaires and the internet originating from outside sources as opposed to the primary user. Statistics highlighting high prevalence rates of SAV within the autism population compared to non-autistic people was a common theme deriving from the following studies. Jones et al. (2012) undertook a review and meta-analysis of data from research studies estimating prevalence rates of 13.7% of SAV amongst disabled children. Most research addressing SAV has been conducted with children with a disability but has not been specific about the type of disability (Kenny, Crocco and Long, 2021). Several studies have addressed the prevalence rates of SAV within the autism population (Brown-Lavoie, Vecili and Weiss, 2014; Cazalis et al., 2022; Gibbs, Hudson and Pellicano, 2022; Griffiths et al., 2019; Kildahl et al., 2020; Mandell et al., 2005; Sala et al., 2019). These studies have been consistent in their findings and autistic individuals and those with LDs are at a heightened risk of SAV compared to the general population. However, there is a scarcity of evidence-based data regarding this matter (Joyal et al., 2021).

Mandell et al. (2005) conducted a study addressing child abuse in autistic children and the findings exposed that caregivers reported that 18.5% had experienced physical abuse and 16.6% of autistic children had been sexually abused. Autism Society (2006) based in Maryland, USA, surveyed over one thousand five hundred autistic individuals and their caregivers revealing that 35% were victims of crime, 13% reported being sexually abused, 8% sexually assaulted and 7.5% were victims of domestic violence.

The likelihood is that autistic children and those with LDs are mistreated at a rate of two to three times more than those who are non-autistic (Kildahl et al., 2020). The studies broadly agree, despite some small variability from different locations. The difference in participants reporting offer a level of generalisability to the figures in a broad sense, but there are likely to be under-reports as they are not first-hand accounts.

A study by Brown-Lavoie, Vecili and Weiss (2014) involved psychologists in Canada who asked ninety-five autistic adults whether they had been raped, felt compelled to have sex or if they had been sexually abused. It was hypothesised that autistic individuals would be sexually victimised compared to the comparison group consisting of one hundred and seventeen non-autistic participants. Chi square analyses and odds ratios were utilised to test the hypothesis. It found that autistic individuals experienced undesirable sexual contact almost three times more than the comparison group, 78% of sexual victimisation occurred within the autism population and were greater compared to 47.4% for non-autistic people. In parallel to the general population, the literature regarding SAV within the autism populace mainly addresses SAV in females compared to males. Autistic males are possibly more susceptible to SAV compared to non-autistic men. Similarly, autistic females are more likely to be exposed to SAV compared to non-autistic women (Brown-Lavoie, Vecili and Weiss, 2014).

In consonance with other limited large-scale studies, Griffiths et al. (2019) conclude that the prevalence rates of coercion and forced sexual activity were substantially higher than the non-autistic group. They conducted an international study comprising four hundred and twenty-five autistic adults and two hundred and sixty-eight non-

autistic adults. Cazalis et al. (2022) conducted an online questionnaire within the French community exploring sexual abuse prevalence and sexual victimisation. Two hundred and twenty-five autistic women voluntarily participated and they were over the age of seventeen. The Sexual Experiences Survey-Short Form Victimization was utilised and the findings revealed that women within the general population are affected by SAV at a rate of 30% and two to three times more for autistic women. A study by Gibbs, Hudson and Pellicano (2022) explored the scope and nature of the experiences of violence that were reported by autistic adults. Participation comprised two hundred and fifty adults aged nineteen or above who could read and write in English. It included one hundred and twenty-two autistic participants self-reporting an independent clinical autism diagnosis (n = 104) or self-identified as autistic without a professional diagnosis (n = 18). Additionally, one hundred and twenty-eight non-autistic adults participated. A questionnaire was completed about their experiences from the age of fifteen regarding sexual harassment, stalking and sexual and physical violence. The results revealed that there were higher incidences of all types of violence in multiple forms with a repetition of the same type of violence within the autistic sample. Regardless of location, the studies indicate that the autism population are actively vulnerable to abuse both inside and outside of the UK in comparison to non-autistic people.

Fundamentally, these few large-scale studies incorporating the experiences of autistic adults are representative of autistic sexual vulnerability, universally. Open discourse may serve towards addressing the barriers associated with breaking the silence and taboo of SAV whilst battling to eradicate this heinous crime.

## **2.7 Sexual abuse and violence from first-hand accounts of late diagnosed autistic survivors**

Due to the lack of autistic voices in academia regarding SAV, I searched the grey literature producing some interesting narratives from the autism perspective in the UK and globally. It served a valuable purpose in filling the gaps that were missing in the empirical literature regarding the experiences of autistic survivors. Three publications came closest to autobiographical accounts from autistic survivors of SAV and they were produced by Carbajal and Praetorius (2020); Lilley et al. (2022); and Morgado Ramirez (2022). The nature of these publications markedly demonstrated the authenticity of the experiences of autistic survivors of SAV; thus, raising awareness from their perspective. They contained interesting data and several themes emerged including the symptoms of autism exacerbating sexual vulnerability; impacts of adulthood autism diagnosis; normalisation; confusion of emotions; victim-blaming; physiological and psychological effects; being disbelieved; interpersonal and multiple victimisation; inability to form relationships; consent; and a journey of self-discovery.

The first publication was by Carbajal and Praetorius (2020) and they conducted a case study exploring how a sexually abused autistic child (Annie, a pseudonym) processes what she endured. The similarities and differences regarding her experience is compared to those of non-autistic children. They utilised secondary qualitative data focusing on Annie's journal of her experiences on the internet reflecting from childhood until adulthood. She survived a cycle of SAV by family friends, gang raped by acquaintances and she prostituted herself.

Carbajal and Praetorius (2020) utilised a grounded theory (GT) approach and several themes emerged consistent with the experiences of SAV within the general

population. The themes comprised normalisation and the grooming process; the interpretation process; the occurrence and reasons for abuse; objectification; feeling trapped; substance misuse; perpetrators; and atypical (Carbajal and Praetorius, 2020). The findings revealed that autistic children experience SAV in the same way as non-autistic individuals, but trauma is processed differently by autistic individuals. The theme 'atypical' elucidated the difference in being autistic compared to non-autistic individuals. The symptoms associated with autism further compound the complexities of CSA. Annie's normalisation of SAV was heightened because of being autistic, albeit caution is reserved as this interpretation is that of the non-autistic researchers. She was victim-blamed as she was told that being autistic was the reason why she experienced SAV. The single case study aided the understanding of Annie's phenomenon, producing interesting data but it had limitations. As a single case it limited the area of research, hence there are implications for its trustworthiness. This is significant particularly as it was secondary data used from the internet whereby Annie was an unknowing research participant. Her data was used in a way that she did not intend and had implications for its robustness. The researchers were not positioned to follow up further questions or clarification affecting the reliability of the analysis.

The publication by Lilley et al. (2022) afforded an insightful qualitative oral history study documenting the experiences of autistic Australian adults who had not got a clinical autism diagnosis until after the age of thirty-five. The study comprised twenty-six participants born before 1975 in an epoch where little was known about autism. Autistic researchers interviewed each participant and autistic and non-autistic researchers transcribed and analysed the data utilising the six-steps that were outlined by Braun and Clarke. Four over-arching themes emerged and the third theme 'the

suffering self' highlighted that some of the female participants had disclosed historical SAV. One participant expressed that enduring CSA affected her whole life. Another participant explained that her experience of SAV from the age of twelve altered her. She was a reserved girl engaging well in studies to becoming an alcoholic at the age of fourteen. The abuse affected her ability to form friendships as she regarded herself as not being a nice person. She reconciled with her experiences and perceived that receiving an autism diagnosis was helpful. She recognised her acquiescence due to being autistic and commented:

I can forgive myself for the sexual abuse that I was put through... because I understand how it came about and how easily I was manipulated. And I think it must be a very common thing for girls like us. (no pagination)

The study highlighted that for most of the women a formal diagnosis positively impacted upon their self-perception emphasising their strengths (Lilley et al., 2022). Similarly, Bargiela, Steward and Mandy (2016) revealed that the findings from their study elucidated that four women utilised their Asperger's diagnosis as a tool giving them the confidence to assert their views. Before diagnosis they remained silent but since diagnosis they had the self-assurance to ask for clarification if they were uncertain about a situation. One woman had the confidence to say, no (Bargiela, Steward and Mandy, 2016). Age of diagnosis is significant regarding the risk factors of SAV because individuals may already be in a relationship (Joyal et al., 2021). They could stay in abusive relationships due to co-dependency, fear of isolation, and financial security.

The publication written by Morgado Ramirez who is a Latinx autistic survivor of SAV focuses on the Latinx population living in the USA. She narrates her experiences of

symptoms associated to autism that further compound the complexities of CSA. It supports the empirical research evidencing the effects of repeated interpersonal victimisation experienced by many autistic individuals (Codina, Pereda and Guilera, 2022; Pearson, Rose and Rees, 2023; Roberts et al., 2015). Morgado Ramirez reflects from childhood into adulthood chronicling her survival of abuse. Growing-up in a culture that is ignorant about autism led her on a journey of self-discovery. She was sexually coerced but did not recognise it as abuse which concurs with limited studies in the empirical literature. She only recognised healthy relationships when she met her husband. However, misunderstandings in their relationship emerged regarding being autistic. This corresponds with the work by Hendrickx (2008) highlighting the difficulties that may be faced by autistic individuals who are in a relationship with a non-autistic person and vice versa. Morgado Ramirez was diagnosed aged thirty-five. Her diagnosis was the catalyst in the sense making of her past experiences, and it led to an identity crisis. She acknowledges that she was not to blame for her abuse, contrary to the experiences of many survivors who self-blame.

Autism diagnosis in adulthood is a common theme from the above publications and consistent with the experiences of the following autistic bloggers who survived SAV. Sarahhdbristol (2019) received an autism diagnosis in her forties. Annie was diagnosed in early adulthood following two misdiagnoses, and Anon UK Male (2019) aged thirty-nine was diagnosed at thirty-seven. Camila (2019) received diagnoses of autism and mental health in adulthood. Sarahhdbristol hoped that her experiences of a late autism diagnosis and SAV would contribute towards changing people's attitudes to protect autistic females.

The bloggers' aftermath of SAV was not dissimilar to non-autistic survivors. Sarahhdbristol metaphorically refers to her experiences as a "tsunami" and she self-harmed. She experienced anxiety, depression, panic attacks, anger, pain, trauma, regret, shame, and solidarity. Solidarity indicates accepting her experiences. Aspiewolf was in a dark place. Anon UK Male endured SAV aged thirteen/fourteen, and it took him twenty-five years to understand what happened and has counselling. Mark Kent has physiological problems and has myalgic encephalomyelitis (M.E.) and also bladder and bowel problems. Interestingly, the physiological aspects of SAV are seldomly discussed in the literature.

Sarahhdbristol's lack of understanding concerning consent played a significant role in understanding sexual boundaries, and responses to disclosure blurred the lines of consensual issues. Sarahhdbristol and Morgado Ramirez fell prey to SAV because of being literal. Aged fourteen, Sarahhdbristol was coerced into having sex as she believed everything she was told by her abuser. She realised that she had been raped but her step-father accused her of lying. Due to her literalness, she deemed he was right. After thirty-three years she has learnt safe boundaries "I haven't just survived, I now thrive and embrace the strengths that autism gives me".

The patterns that emerged from the bloggers were experienced by Christine McGuinness, an autistic CSA survivor. She promoted her celebrity status as a model and a television personality raising awareness of autistic women in her latest documentary (*Unmasking My Autism*, 2023). Christine received an autism diagnosis aged thirty-one. Late diagnosis resulted in feelings of confusion in understanding which part was her, and struggled with defining who she mostly was. Her vocation was

to make sense of her authenticity. Similarly, prior to Sarahhdbristol's autism diagnosis, she was confused and since being diagnosed has been on a journey of self-discovery.

Fostering first-hand knowledge from the autistic perspective provides a deeper understanding of how autistic survivors are affected by SAV. The bloggers wrote about the effectiveness of blogging to have their voices heard. It was a powerful mode of communication, and they reported that it brought them a sense of acceptance and it was a cathartic experience. Creative ways of communication can benefit those from marginalised groups who may have difficulties in effectively expressing themselves. In turn, it suffices in raising awareness of taboo topics, and society can benefit from the knowledge sought from their phenomenon. This added a nuanced and in-depth insight into the lives of autistic survivors. Sharing their experiences exposed them to other autistic individuals' stories of SAV.

The bloggers effectively connected with each other, and Anon UK Male thanked Sarahhdbristol for talking about her experiences of SAV acknowledging that it was under discussed. Mark Kent was thankful to hear Sarahhdbristol's story and wrote that people do not see the daily effects of SAV. Camila appreciated hearing their stories because they made her feel less isolated, and she has been given hope by bloggers in similar situations. Each blogger empathised with each other's stories dispelling the myth that autistic individuals cannot empathise.

## **2.8 Autistic sexual vulnerability**

The grey literature and the bloggers exposed a fundamental gap in the academic research concerning autistic sexual vulnerability compared to non-autistic people. A

common theme emerged highlighting the detrimental effects of not receiving an autistic diagnosis in childhood, and it possibly negatively impacted upon them being sexually vulnerable. Autistic individuals' vulnerability may inadvertently put them at risk of perpetration which may be due to autism (Payne et al., 2020). They could misunderstand the social norms expected by non-autistic people, and they may have the inability to recognise inappropriate behaviour. The literature review identified a large scope of literature concerning autistic vulnerability to risk. Contrastingly, there were limited research publications regarding sexual vulnerability within the autism population, and it emerged as a central theme. Familiar patterns alongside this theme comprised autistic masking; the importance of human interaction; and the resilience of autistic survivors of SAV who remain positive.

The empirical research evidenced that the autistic population are vulnerable to many risk factors and easy targets for victimisation, but studies concerning autistic sexual vulnerability were limited. However, this gap was filled by the large scope of grey literature. Jessica Horner (2023) wrote an article about Grace Tame who is from Tasmania. Grace is autistic and renowned for being a survivor of CSA. She is an advocate and in 2021 she was named Australian of the Year. She talked about feelings of confusion whilst surviving SAV, and also self-doubt because of the subtlety of the groomers. Despite being sexually vulnerable, she acknowledges that being anorexic added to her vulnerability. However, she remains positive and she shares the same perspective as myself which I have previously discussed:

I've found that neurodivergent people are some of the most empathetic, some of the most fascinating, some of the most educative, brilliant people I've ever met and connected with.

The bloggers candidly wrote about their experiences of autism and sexual vulnerability. Interestingly, Anon UK Male and Sarahhdbristol describe themselves as either a 'survivor' or 'victim'. Anon UK Male's perception is that he is "a vulnerable person who was taken advantage of". Sarahhdbristol wrote that exploiting vulnerability emphasises how deep rooted the trauma is. Notwithstanding the paucity of research regarding autistic sexual vulnerability, there has been a growth in the literature, together with various attributing factors (Bargiela, Steward and Mandy, 2016; Brown, Peña and Rankin, 2017). There are gaps in research linked to understanding the risk of SAV in autistic individuals and the contributing variables (Brown-Lavoie, Vecili and Weiss, 2014). Similarly, Kenny, Crocco and Long (2021) acknowledge the lack of exploration concerning autistic SAV and the findings of their research elucidated several characteristics linked to autistic sexual vulnerability.

Autistic individuals may be at an increased risk of interpersonal victimisation spanning their lifetime (Roberts et al., 2015) in addition to experiencing multiple victimisation (Codina, Pereda and Guilera, 2022). This adds to the sexual vulnerabilities faced by autistic individuals, particularly for those institutionalised or dependent upon support. Those in positions of hierarchy may abuse their power and trust, further compounding the risk of SAV in vulnerable people. The Independent Inquiry into Child Sexual Exploitation in Rotherham in the UK (1997-2013) exposed that children accessing residential services and schools introduced other children to perpetrators. Children with disabilities who do not live at home are vulnerable to isolation due to being separated from those closest to them (Miller and Brown, 2014). This concurs with the Child Exploitation and Online Protection (CEOP, 2013) highlighting augmented power imbalances in residential care due to victims being isolated from their support

networks. Miller and Brown (2014) identified a gap in research concerning the experiences of disabled children in the child protection system. Autistic people have increased contact with service providers compared to non-autistic individuals and may be targeted by opportunist offenders (Edelson, 2010). This is in accordance with the CEOP (2013) thematic assessment report (which does not explicitly focus on children with disabilities) revealing that children are at risk of SAV whilst institutionalised, and at additional risk if it goes unnoticed and unreported when discovered. The role of the CEOP centre is to protect children from SAV and issues regarding online and offline safety, spanning inside and outside of the UK. Living in an era of digital technology whereby social media can be accessed by most countries (with only a few banning it), the media draws attention to the prevalence of SAV globally.

Although this research does not intend to discuss autistic perpetrators, it is worthy of a brief mention. The symptoms of autism may inadvertently position them vulnerable to perpetration due to misunderstanding appropriate sexual relations. Difficulties in social functioning and a desire for intimacy can precipitate inappropriate sexual behaviour (Mercer and Allely, 2020). Payne et al. (2020) undertook a study comprising nine autistic sexual offenders from England and Wales who were in prison and probation services. Semi-structured interviews were conducted and thematic analyses were undertaken. Themes emerged concerning the symptoms of autism including social difficulties; misunderstandings; difficulties in sex and relationships; and a lack of control and disequilibrium. It highlighted that they offended due to their difficulties in social skills; weak central coherence; and misunderstanding their actions.

Sarahhdbristol explained that autistic individuals may experience a type of vulnerability that is unique across their life-span. She speaks on behalf of herself and other autistic individuals articulating the need for human interaction, but the misunderstandings between autistic and non-autistic people can lead to autistic sexual vulnerability. To stay safe, many autistic people mask parts of themselves resulting in exhaustion (Pearson, Rose and Rees, 2023). An important theme to emerge from the literature review and the bloggers was autistic masking. Evidently, Christine McGuinness masked as she referred to shedding her old identity to discover what she considered to be her authentic self. Sarahhdbristol imitated others to fit in but she was unable to recognise social cues. She did not socialise well and masked everything by pretending to be confident.

The female autism phenotype may compromise a person's safety due to the symptoms of autism and misinterpreting inappropriate sexual behaviour in themselves, and others. Autistic individuals tend to mask their authenticity which can negatively impact upon their safety, particularly if they desire acceptance and may imitate inappropriate behaviour. Bargiela, Steward and Mandy (2016) utilised Framework Analysis exploring the effects of the lack of recognition of female autism phenotype. Fourteen autistic women aged between twenty-two to thirty who were diagnosed late in adolescence or adulthood were interviewed, and they narrated their experiences of 'pretending to be normal'. The findings exposed vulnerabilities within the sample as a consequence of female undiagnosed autism and widespread SAV. The purpose of the study was to gain knowledge regarding the female autism phenotype and the impact it has on recognising autism. An inductive qualitative approach was utilised enabling the generation of innovative concepts and to deepen the knowledge of prevailing ideas. Nine of the participants had been sexually abused

and half of them were in relationships. Three women were raped by a stranger and another was groomed. The data elucidated several interlinked reasons compromising their safety including mimicking flirtatious behaviours; misreading the intentions of others; feelings of isolation impacting upon their abilities to develop safety strategies; desire for acceptance added to their susceptibility to exploitation; uncertainties regarding social rules; inability to recognise that they could say no to unwanted advances; unaware of how to say no; and unable to escape unhealthy relationships.

## **2.9 Gender, diversity, and sexual identities**

A common theme to emerge from the research evidence indicates that autistic females are at a greater risk of SAV than their non-autistic counterparts. There is also a glaring gap in the empirical literature regarding autistic male survivors. Hypothetically, autistic men are at a greater risk of being perpetrated compared to non-autistic males. Although this is lacking in the empirical research, the grey literature filled this gap as autistic male bloggers wrote about their experiences. Gibbs, Hudson and Pellicano (2022) recognise that studies exploring the violation of autistic adults have chiefly addressed women who have experienced SAV or comprised small samples which have prohibited gender comparisons. They found that there were differences in the gender regarding the patterns of violence. Physical violence was more predominant in men whilst women were largely sexually violated, and this was evident in the non-autistic group but not the autistic participants (Gibbs, Hudson and Pellicano, 2022).

Cazalis et al. (2022) claim that autism itself is not the basis for autistic women experiencing SAV but a factor increasing their vulnerability. A book by Sarah Hendrickx (2008): *Love, Sex & Long-Term Relationships: What People with Asperger*

*Syndrome Really Really Want*, explored the experiences of autistic adults within the realms of sex, gender and relationships and examined typical symptoms associated to autism. Sarah does not have a diagnosis of autism but her partner has Asperger's syndrome. She utilises her own experiences and those of her partner with some people known to her as a method of data collection, and also data from surveys and interviews. The research sample comprised thirty-six autistic males, four autistic females and twenty-seven non-autistic women who had autistic partners ranging in age from their twenties to seventies. A questionnaire was completed but some questions were unanswered. The findings reported that half of the autistic women experienced some form of SAV and were at greater risk compared to the non-autistic sample due to misunderstanding signals, and believing what they are told by predators (Hendrickx, 2008).

The empirical literature gave insight into the complexities that individuals with gender and disability issues may experience and it emerged as an important theme. The published and grey literature, and the bloggers highlighted that autistic people are sexual beings despite the outdated myths that run counter to this but evidently, there are implications regarding sexuality, gender and autism. It is important to consider sexual practices which may deviate from what many people regard as the norm. It must not be assumed that autistic people only engage in vanilla sex (Boucher, 2009). Asexuality, agenderism, androgyny, and transgenderism are commonly linked with autistic individuals, and there may be confusion regarding sexual identities. Lawson (2015) suggests that addressing their biological sex and gender helps them to identify with their true gender identity.

The intersect of disability and sex is controversial because many people believe that disabled individuals do not engage in sexual activity let alone engage in sexuality perceived as diverse (Boucher, 2009; Nakkeeran and Nakkeeran., 2018). There is growing literature addressing gender diversity and sexual identities within the autistic population, but there are limited studies addressing how this may impact upon their sexual vulnerability. This is concerning due to the recognition of the diversity within modern-day society. Marginalised groups are frequently discriminated against, but adding disability such as autism into the mix compounds the complexities concerning the victimisation of gender and sexual identities. This can further stigmatise an already marginalised group adding to the interpersonal traumas (IPTs) that they may experience.

There is multiple and intersectional discrimination regarding gender and disability (Davaki et al., 2013), and high prevalence rates of autistic people who are attracted to multiple genders (Byers et al., 2013). Autistic women and gender minorities are predominantly vulnerable to IPTs and they are detrimentally affected (Reuben, Stanzione and Singleton, 2021). Autistic females may not understand if sexual attention is something that they want or is expected of them (Bargiela, Steward and Mandy, 2016; Kofmel and Blakemore, 2015). This was the experience of Lawson (1998; 2005) who is autistic and as a child was sexually abused for many years. At the time Lawson was a female and did not recognise it as abuse and deemed that she was complying with the abuser. Lawson did not have an autism diagnosis when she was a child who was exposed to sexual victimisation. This is significant because there are limited studies addressing diagnosis in adulthood and the influence it may have on autistic sexual vulnerability. Lawson has since transgendered and identifies as a

male, bringing attention to the scarcity of literature concerning male experiences of SAV in the autistic population.

Pecora et al. (2020) recognise the growth in the presentation of autistic women who have more gender diversity and sexual identities compared to non-autistic individuals. They conducted a study examining negative experiences in autistic and non-autistic women regarding their gender identity and sexual orientation, comprising two hundred and ninety-five female participants. The sample included one hundred and thirty-four autistic adults aged between eighteen and fifty-six. One hundred and sixty-one non-autistic females aged between eighteen and forty-eight participated. The data collected were via a single internet-based questionnaire consisting of a diagnostic screening tool and The Sexual Behaviour Scale-III (SBS-III) measuring sexual and romantic functioning. The findings revealed that the autistic participants were exposed to heightened sexual risks and vulnerabilities including victimisation and abuse due to identifying in a multi-minority group (Pecora et al., 2020). These findings concur with studies by Lewis et al. (2021) and Maggio et al. (2022) recognising that autistic individuals are more likely to be gay, lesbian, bisexual, asexual, and other sexual orientations compared to non-autistic people. Lewis et al. (2021) state that autistic individuals identifying as sexual minorities are positioned in the intersection of two high-risk groups, increasing vulnerability in sexual relationships because of a double minority complicating their identity formation. Maggio et al. (2022) recommend sexual health and education for this group to improve their quality of life and to minimise risky behaviours.

## **2.10 Barriers to disclosing sexual abuse and violence**

An important theme to emerge from the literature review was gender diversity and sexual identities; thus, illuminating the gap in research concerning the barriers that influence whether autistic sexual minority survivors disclose SAV. This theme highlights the challenges faced by marginalised groups regarding those identifying as lesbian, gay, bisexual, transgender, queer, questioning, intersex and asexual (LGBTQIA+), and women of colour have been unrecognised (McMahon and Seabrook, 2020). Edwards et al. (2022) recognise that sexual and gender minority (SGM) individuals commonly endure SAV but there are limited studies addressing their disclosure experiences. They acknowledge the barriers to disclosure regarding those exclusive to SGM individuals including the fear of being outed, and psychological negative impacts due to social reactions in contrast to positive responses which helps recovery (Edwards et al., 2022). The findings corresponded with a study by Ollen et al. (2017) who examined the sexual minorities of college students. The participants comprised fourteen students from a sexual minority aged eighteen to twenty-four and two focus groups were conducted. Research focusing on SAV is largely concerned with heterosexual students, but the victimisation rates amongst sexual minorities were the same or higher than heterosexuals. The findings revealed an overlap between the risk and protective factors with heterosexuals, but there were additional factors exclusive to the sexual minorities including societal, community and psychological barriers in seeking help. Being part of a minority group has additional disadvantages due to stigma and discrimination. Adding SAV into the mix regarding the aforementioned can instil fear into the individual upon their disclosure decision due to further marginalisation. There are parallels with the barriers to disclosure for minority groups and autistic individuals and/or those with a disability.

Furthermore, some groups may experience added barriers to disclosure due to religious, cultural and diverse backgrounds.

Disclosure can occur in four different categories including purposeful, accidental, delayed or prompted (Sorsoli, Kia-Keating and Grossman, 2008). It is challenging if the individual is unaware that they have been abused. Children usually disclose to a friend or family member but generally to their mother, and disclosure is often evoked after an inquiry about a physical complaint. Radford (2011) undertook a study and six thousand young adults, teenagers, children, and parents of youngsters were interviewed. The findings revealed that one in three children disclosed SAV. If the child does disclose but receives a negative response, it could heighten their anxiety and disclosure may be retracted (Hershkowitz, Lanes and Lamb, 2007). This is concerning because when children disclose to an adult who can protect them it can stop the abuse (Radford, 2011). Clinicians recognise that acknowledging and disclosing memories, thoughts and feelings associated with abuse can aid recovery (Sorsoli, Kia-Keating and Grossman, 2008). Children can be psychologically affected if abuse is undisclosed (Radford, 2011). Kofmel and Blakemore (2015) identify ways that could assist autistic individuals in reporting abuse including educating them about emotional, sexual and physical boundaries, healthy platonic relationships, and communicating feelings through symbols instead of verbal dialogue.

Autistic individuals may not present as a typical survivor of SAV. The empirical research lacks consideration of the added difficulties they could experience due to their symptoms of autism including communication difficulties; possible lack of eye contact; unusual display of emotions; and they may be accused of false allegations

(Kofmel and Blakemore, 2015). This was the case for blogger Sarahhdbristol as her step-dad did not believe that she had been raped. It had implications for her experiences with future boyfriends who forced themselves upon her. She did not see the point in telling anyone for fear of being disbelieved and she felt deserving of abuse.

Communication difficulties can negatively impact disclosure with up to 50% of autistic children being non-verbal (APA, 2000). Furthermore, autistic individuals may have fewer people to tell and ways of disclosing (Sullivan and Knutson, 2000). They could experience difficulties in expressing their emotions and making their needs known (NAS, 2016). The NSPCC Childline helpline (2022/23) were contacted by fifty-nine thousand and two hundred and eighty-two contacts from individuals with child welfare concerns but using a telephone may be difficult for autistic people (Kofmel and Blakemore, 2015). It is important to understand that abused children may not be old enough to use a telephone and/or be aware they are a victim (Sanderson, 2006).

There is a plentiful supply of literature addressing the barriers of disclosing SAV in general (Allnock and Atkinson, 2019; Griffin, Wentz and Meinert, 2022). Although the autistic and general population face similar barriers of disclosure, they may be intensified for autistic individuals due to their symptoms of autism. The barriers occur in numerous domains of experience and are encountered throughout a lifetime (Sorsoli, Kia-Keating and Grossman, 2008). SAV is a health risk and the victim may face psychological trauma as they contemplate disclosure enabling them to get support, divided by risking negative reactions (Jonzon, 2006). Delayed disclosure is linked with intrafamilial abuse; being close to the perpetrator; having multitude perpetrators; age of onset; and severe abuse (Jonzon, 2006). Disclosure can be a

challenging process for the survivors and the people they disclose it to. It may be a traumatic experience and if it is not effectively managed it can be retraumatizing. McMahon and Seabrook (2020) recognise why individuals do not disclose including fear of the offender; unwilling to inform family or others; lack of evidence; fears concerning the CJS; unawareness of the reporting process; experiencing PTSD; depression; and characteristics of the assault such as those committed by strangers or the result of an injury. Fear is a key factor in non-disclosure due to the survivor feeling frightened of the abuser as they may threaten to kill their family (Faulkner, 2012). Furthermore, the masks of masculinity prevent men from reporting SAV due to feeling shame, embarrassment, disempowerment, and emasculation with the added stigma regarding homosexuality (Hlavka, 2016).

Rape myth acceptance can be influential in the disclosure of SAV and also the ideology of victim-blaming (Lichty and Gowen, 2021). Male and female survivors of SAV frequently experience secondary victimisation by victim-blaming and negative reactions by their social environment (Mulder and Bohner, 2022). Victim-blaming is rife and survivors either blame themselves and/or they may be blamed by the perpetrators, or the CJS (Schiewe, 2019). This is because if a victim physically freezes whilst being violated, it may be deemed that they had consented (Kozłowska et al., 2015; Schiewe, 2019). This may have implications for the survivor disclosing because they may fear being blamed as they never said, no. Just because a person does not say no, does not mean that they have consented. Metz, Myers and Wallace (2021) acknowledge the grey area in the navigation of sexual intimacy, and a stark line between consenting and not consenting to sex covering a spectrum of sexual consent to sexual assault.

The grey literature search produced an article about a famous pianist who is on the autism spectrum. James Rhodes (2015) articulates his awe-inspiring revelations of childhood SAV within his autobiography. He reveals his tiresome journey of disclosure and the battles he faced with the law courts and his ex-wife to permit publication of his story. In today's modern society whereby, one would hope that freedom of speech is permissible, it was debatable as to whether his experiences ought to be publicised. Objectors to the publication deemed that it was a private matter and should not be in the public domain. As it had happened many years ago, it was thought that it must be kept quiet. Rhodes' fight for recognition impacted upon his mental health and suicidal ideation and it was his passion for music that saved his life. This story reflects the damage that can be caused by silencing a survivor. This is supported by the published literature addressing the importance of disclosure enabling the survivor to heal (Goodyear-Brown, Fath and Myers, 2012).

There is increased literature exposing the retraumatisation of victims whose disclosure to the authorities has intensified their suffering (Hayes et al., 2011; Hovath et al., 2014; Plotnikoff and Woolfson, 2009; Westcott and Page, 2002). Eastwood (2003) claims that it is reprehensible that victims giving evidence can result in ruthless and hostile reactions by the CJS with bullying tactics to "belt them up" (p. 5) before the trial. Research undertaken by Hayes et al. (2011) revealed that 51.4% of children were distressed about their court experiences after the trial. Victims of abuse seeking legal, medical and mental health services support are often secondary victimised due to professionals engaging in behaviours that had damaging effects on them (Campbell and Raja, 1999). Similarly, Lorenz, Kirkner and Ullman (2019) state that there are many survivors who have experienced secondary victimisation by the law. This

indicates that there is a requirement for improved treatment of survivors within the CJS to prevent retraumatisation. It is problematic that they are exposed to retraumatisation due to the shortcomings of professionals who may not have the knowledge or skills to support them. A lack of autism training and understanding of how individuals are affected by their diagnosis can inadvertently retraumatise a survivor, particularly if they display behaviours atypical to non-autistic survivors. Personal accounts from autistic individuals could help in designing the protocols to assist verbal and non-verbal disclosure of survivors (Edelson, 2010).

### **2.11 The convergence of autism, sexual abuse and violence, mental health, trauma, and PTSD**

A major theme to emerge from the literature review was the psychological aftermath experienced by SAV survivors. Individually, there is a wealth of literature regarding autism, SAV, mental health, trauma, and PTSD. The intersections could have implications for recognising the signs of SAV and misattributing them to the symptoms of autism. However, there is a scarcity of literature addressing these convergences and little is known about how they manifest in autistic survivors. This neglect of literature is concerning, particularly as autistic people are at greater risk of SAV and trauma compared to non-autistic individuals. This is supported by Roberts et al. (2015) who conducted a population-based longitudinal cohort, the Nurses' Health Study II (N = 1,077). It identified for the first time a convergence of autistic traits, abuse in childhood, trauma, victimisation and PTSD. The researchers considered past events of the aforementioned amongst women in adulthood. The 65-item Social Responsiveness Scale measured autistic traits estimating odds ratios for abuse comprising sexual, physical and emotional abuse in children, and symptoms of PTSD

by quintiles of autistic traits. The findings exposed that 40.1% of women with autistic characteristics had probably been sexually abused and 25.4% pressurised into sexual contact. This population was at an increased risk of PTSD following a trauma.

Trauma and PTSD may develop after experiencing a life-threatening event. The DSM-5 (APA, 2013) defines trauma as “actual or threatened death, serious injury, or sexual violence” (p. 271). Trauma can be experienced across an autistic person’s lifetime because being autistic in itself can be traumatising, and this was the case for blogger Annie. This largely goes unrecognised, and autistic individuals may experience traumatic situations that would unlikely affect non-autistic people (Au-Yeung et al., 2018; Gravitz, 2018; Kerns et al., 2022). This adds to the complexities regarding autism and SAV because little is understood about how autistic individuals process trauma. Annie highlighted that being autistic affected her processing ability and deceived people into thinking that autistic children are unable to understand their trauma. She deemed that people who knew her thought her experiences were less traumatic because she was unable to process them. Contrariwise, Annie was unable to reprocess her trauma which was worsened by repetitive sensory input. She could not eradicate the trauma because of the repetitiveness of the symptoms associated to autism and trauma. This has implications regarding the recovery for autistic survivors if they are reliving SAV. SAV compounds trauma and PTSD in autistic individuals, but it is a much-understudied topic (Kerns, Newschaffer and Berkowitz, 2015).

Reuben, Stanzione and Singleton (2021) acknowledge that IPTs are reported by many autistic adults including physical or sexual assault and are commonly related to PTSD and dissociation. They conducted a study to obtain greater knowledge regarding why

they are more susceptible to trauma and how they are affected by it. Their study comprised six hundred and eighty-seven self-identifying autistic adults. To ascertain their experiences of trauma and symptoms of mental health, they were asked to complete an online survey. The findings exposed that 72% of the participants experienced sexual assault; unwanted sexual experiences; or physical assault; 44% reported PTSD including 50% having IPT; 93% experienced mind-based dissociation at a high level; and 32% had body-based dissociation at high levels. There were no differences between participants that had a professional autism diagnosis and those who did not.

There is a distinct lack of knowledge regarding how the symptoms of autism manifest in an autistic survivor. This is further complicated by associated comorbidities including depression, anxiety and obsessive-compulsive disorder (OCD). Comorbidities related to autism can compound problems with mental health in autistic individuals and add complexities if they have experienced SAV. Approximately 40% of autistic children have a diagnosis of at least one comorbidity (Paul et al., 2018), and the convergences of the symptoms are predominantly overlooked (Gravitz, 2018). It is important to consider the co-occurring mental health difficulties that can be experienced by autistic individuals because it can have implications for accurate diagnosis and treatment interventions (Brede et al., 2022). The convergences can affect various aspects of their mental health including accurate diagnoses, differential diagnosis, diagnostic overshadowing and therapeutic interventions. It may have implications regarding the recognition of SAV in autistic individuals as the symptoms of each of the convergences are similar. Therefore, SAV could go unnoticed and may be misattributed to autism. This highlights a significant gap in the empirical research and more knowledge is required to effectively support autistic survivors. An online

study undertaken by Au-Yeung et al. (2018) surveyed four hundred and twenty adults about whether they agreed with their mental health diagnoses. It revealed that autistic individuals were more likely than non-autistic people to disagree with them. Thematic analysis was undertaken and it found that this was because autism was misattributed to mental health problems and misdiagnosis, and diagnostic overshadowing was concerning. Health care professionals prioritised the mental health of autistic individuals as opposed to the underlying needs of autism, and the psychosocial needs were unaddressed (Au-Yeung et al., 2018).

PTSD is complicated but the likelihood of diagnosing it in autistic individuals is more difficult (Paul et al., 2018). Treating autism and PTSD separately in individuals with both conditions can be difficult because of the blurred boundaries between them; therefore, effective treatment comprises treating them simultaneously (Gravitz, 2018). Due to PTSD being highly prevalent in those who have experienced CSA, treating PTSD is a suitable starting point in exploring effective strategies for autistic child victims (Carbajal and Praetorius, 2020). There is ambiguity regarding the treatment of autistic people with PTSD due to the complexities related to autism and a lack of information in this area. A related theme “The interpretation process” was at the core of understanding the abuse from the victim’s perspective as they try to organise their trauma (Carbajal and Praetorius, 2020, p. 11).

Some researchers acknowledge that there is extensive literature regarding trauma and PTSD, but there are limited studies addressing the psychological aftermath of trauma and PTSD in autistic individuals (Gravitz, 2018; Kerns, Newschaffer and Berkowitz, 2015). They may be at an increased risk of the development of PTSD due

to experiencing trauma (Dell’Osso, Lorenzi and Carpita, 2021), and more research is required addressing the mental health needs of autistic people. There is a paucity of literature highlighting how traumatic events, especially abuse, strongly affects them (Mandell et al., 2005; Fuld, 2018). It is crucial to consider complex PTSD concerning the possible complexities of the mental health of autistic individuals. The National Institute for Health and Care Excellence (NICE, 2018) state that PTSD and complex PTSD symptoms are the same but emphasise additional ones with complex PTSD including constant issues with keeping relationships; difficulties feeling connected to others; believing they are worthless; deep feelings of shame; and guilt regarding trauma and severe emotional dysregulation (NICE, 2018).

There is a connection between autism and PTSD and it is vital for research to address the prevalence of traumatic stress and distinctive traumatic events in autistic individuals, especially the social sphere (Haruvi-Lamdan, Horesh and Golan, 2018). A study undertaken by Kerns et al. (2022) revealed that some autistic individuals experienced traditional traumas including maltreatment and social marginalisation, whilst others had difficulties with the characteristics of autism and their environment including sensory trauma. Similarly, Paul et al. (2018) acknowledge that autistic individuals with PTSD may experience an extreme fear of hypersensitivities associated with the auditory, tactile, visual and olfactory senses.

## **2.12 A lack of autism awareness of healthcare professionals**

The literature review identified a gap within research regarding healthcare professionals and their understanding of autism. Many are inadequately trained

impacting upon them being able to deliver effective support for autistic individuals. This emerged as a common theme which is concerning, particularly as the lack of knowledge can compound the complexities of an accurate diagnosis and appropriate support. Despite the similarities of the effects of SAV with the autistic and non-autistic populations, it is important to consider the complexities of adding autism into the mix. It makes a recipe for short and long term psychological and physiological problems, and the literature review identified limited studies addressing this in autistic survivors of SAV. This is concerning particularly as autistic individuals are susceptible to abuse and trauma, and PTSD may be intensified. Little is understood about how autistic individuals process trauma and this has implications for healthcare professionals whilst providing therapeutic interventions. Au-Yeung et al. (2018) reported that a lack of autism awareness of healthcare professionals resulted in individuals receiving inappropriate support. This concurs with other studies (Bentley et al., 2016; Brede et al., 2022). High prevalence rates of PTSD in SAV survivors is alarming and it is a strong indicator that treatment requires improvement due to the inadequacy of therapies (Chivers-Wilson, 2006). It is problematic that traumatised individuals are exposed to secondary victimisation due to the shortcomings of professionals who may not have the knowledge or appropriate skills to support them. A lack of autism training and understanding of how individuals are affected by their diagnosis can inadvertently retraumatise a survivor, particularly if they display behaviours atypical to non-autistic survivors. Autism itself can present with challenges in the treatment of trauma because of the symptoms associated to it including cognition, social, behaviour, communication, emotional regulation and disrupted attachment (Gerhardt and Smith, 2020).

Brede et al. (2022) undertook a study to explore the experiences of autistic adults' mental health services and triangulated the views of clinicians, parents and their own perception. It was a systematic review and meta-synthesis of qualitative studies utilising a thematic synthesis approach. The findings elucidated that mental health services were ineffective in supporting autistic individuals and disturbingly, can add further harm. This was the case for Camila who wrote about a psychiatrist who commented that it was uncommon to be raped twice. This negatively impacted upon her self-worth referring to feeling even stranger about herself. The psychiatrist explained that it is unfortunate that autistic females generally experience SAV. This was the catalyst to realising that she had endured SAV on many occasions by random men. Brede et al. (2022) recommend improving mental health service provision consisting of flexibility; more comprehensive and holistic approaches; consideration of the way autism affects the presentation of mental health; tailored support; building up trusting relationships; listening to autistic adults; and empowering them to take agency (Brede et al., 2022). Autistic adults may receive inappropriate support if professionals do not talk to them about their traumatic experiences (Reuben, Stanzione and Singleton, 2021).

Bentley et al. (2016) acknowledge the effect that abuse can have on the mental health of young people and recommend therapeutic support, but the commissioning services are restricted due to a lack of data in this area. Autistic adolescents can be susceptible to trauma because of the difficulties in recognising their own and other people's emotions influencing interpersonal conflict and difficulties forming relationships (Robinson, 2020). Robinson (2018) claims that autistic people may experience pain as a result of emotional misunderstandings with peers that are typically developing,

and identified the limited intervention methodologies concerning the effects of emotional injuries regarding autism and how to work with the aftermath. Robinson's (2020) paper presents an original model of case conceptualisation of relational rupture and repair to clinically guide therapist's whilst working therapeutically with autistic clients. The model was developed through task analysis concerning dyads of therapy and Interpersonal Process Recall sessions of Emotion-Focused Group Therapy with autistic adolescents (EFGT-AS); essentially, this method is helpful concerning their ability to explore self-agency.

### **2.13 A lack of sex education**

A common theme that emerged from the published literature was a lack of appropriate SE for the autism population and their sexual safety. SE is imperative for the autistic population to protect them from SAV, and a factor in safe-guarding them from sexually offending. Leung et al. (2019) identify that globally, existing SE is inadequate and/or ineffective. Universally, SE is a fundamental human right for people with or without disabilities (Rashikj-Canevska et al., 2023). Arguably, it is more important for autistic people because of their vulnerability and susceptibility to violence, injury and abuse (WHO, 2022). The intersection between SE and victimisation should not be underestimated as it has a great bearing on an individual's sexual safety needs (Rashikj-Canevska et al., 2023). Individuals that do not have sexual knowledge are highly susceptible to SAV. Therefore, it is important for those who face discrimination and marginalisation to be aware of the dangers of sex because of their sexual vulnerability.

Whilst discussing SE for autistic individuals, Koller (2000) states that it is a “problem because it is not an issue, or is an issue because it is seen as a problem” (p. 126). SE is a controversial subject in teaching the autism population. It is important that they receive suitable SE, despite the viewpoint of critics opposed to it. Stereotypical and societal beliefs that autistic individuals are perceived as asexual and uninterested in romantic relationships (Schöttle et al., 2017) is contentious. They desire sexual connection and crave intimacy in the same way as their non-autistic counterparts (Hartmann et al., 2019; Sala et al., 2019). Historically, autistic people and those with LDs were viewed as perpetual children needing to be sheltered from sexual knowledge (Cambridge, 1996). The existing literature highlights that instead of sheltering this population from SE they need to be well-informed to minimise the risks of SAV (Brown, Peña and Rankin, 2017; Terrence Higgins Trust, 2016). Contrarily, Cazalis et al. (2022) suggest that educational approaches may not be the most effective way of prevention because many of the victims who experienced SAV for the first time were young in age. This adds to the argument as to the most appropriate age in delivering SE to autistic individuals. They may not receive SE until after they have been sexually victimised or accused of it, and early education would prevent a crisis (Hénault, 2006; Ozonoff, Dawson and McPartland, 2002). “Crisis sex education is a bit like shutting the stable door once the horse has bolted!” (Lawson, 2005, p. 34).

A lack of sexual knowledge is linked to sexual victimisation for the autism populace which places them at risk, in addition to the vulnerabilities of being autistic (Brown-Lavoie, Vecili and Weiss, 2014). Neurodevelopmental individuals including autistic people and those who have a LD merit appropriate sex and relationships education (SRE) because of the risk of SAV (Sala et al., 2019). Pound and Campbell (2017) undertook quantitative and qualitative research examining the effectiveness,

acceptability and sustainability of SRE. They employed a systematic review regarding the efficacy of sexual health programmes and comprised forty-eight studies from the perspective of young people about SRE, and interviews with health commissioners within thirty-six local authorities including case studies and survey data. It revealed that the young people preferred sexual health professionals and peer educators detached from the school to teach them SE as opposed to their teachers (Pound and Campbell, 2017).

There is a gap in the literature addressing effective ways of delivering SE for autistic people due to their individualised needs compared to the general population. There are questions raised about how SE for the autism populace is delivered, and what should be included and by whom. Autistic individuals need to be sexually educated about topics that are mostly covered for non-autistic people (Hartmann et al., 2019). Recommendations for sexuality education include the prevention of CSA but the symptoms of autism add to the difficulties in prevention programming (Kenny, Crocco and Long, 2021).

The NSPPC (2022) highlight the importance of parents/carers being able to protect their children. They can be the key factors in their children's education and protection from sexual harm, indecent exposure, public masturbation and sexually offending. Kenny, Crocco and Long (2021) recognise the difficulties expressed by some parents whilst speaking to their children about sexuality education as many are ill-equipped to teach them about sexuality issues. Similarly, Strnadová, Danker and Carter (2022) reported that some parents lack the confidence in discussing sexuality with their children, and SE may not be delivered as intended due to the beliefs of teachers. The SE needs of autistic people are unique (Loftin and Hartlage, 2015) and individualised

teaching is recommended (Travers and Tincani, 2010). Davies et al. (2022) offer recommendations regarding sexuality education and a one-size-fits-all approach is inadequate, and they advocate for inclusive approaches incorporating the voices of parents and autistic individuals.

Curtiss and Ebata (2016) undertook a survey and approximately three hundred people registered for a workshop about teaching sexuality to those with special needs. The requirements were that the participants used email, Facebook and worked with autistic individuals. There were fifty-nine responses and they received a link to the survey and allocated randomly to one of the two continuing support conditions. The first survey was completed by fifty-five participants and the second one was completed by forty-three participants. It reported that generally people gain sexual knowledge from parents, friends and teachers, but identified that autistic people faced barriers in gaining information from these networks (Curtiss and Ebata, 2016). Brown-Lavoie, Vecili and Weiss (2014) identified similar findings addressing the sources of sexual knowledge. It revealed that autistic people gained less information from social sources but gained knowledge from non-social sources and learnt about sex from the media and not a teacher. These findings are similar to Stokes and Kaur (2005) whereby the SBS was developed and they surveyed parents of non-autistic adolescents (n = 50) and adolescents with high functioning autism (HFA) (n = 23). It identified that autistic individuals learn less about sexuality from their peers compared to non-autistic people. Research undertaken by Haynes (2013) examined the barriers commonly experienced by autistic individuals and sensory sensitivities whilst engaging in sexual activity. The qualitative study employed semi-structured interviews with twelve autistic individuals who spoke explicitly about intimate and taboo aspects of their sexuality. A GT analytical approach highlighted that the participants had missed out on knowledge

from their peers regarding sexuality due to difficulties in making friendships. To educate themselves, 50% of the participants viewed pornography and sex manuals to understand what was required of them sexually. Pornography is viewed by autistic and non-autistic people. Litsou et al. (2021) state the need for further research addressing whether people have a better understanding of the aspects of sex and the mechanics of it by watching pornography compared to those who do not.

An exploratory study was undertaken by Joyal et al. (2021) into the largely unknown self-report sexuality of autistic individuals, and one hundred and seventy-two males and female adolescents and young adults participated. An online version of the SBS-Third edition was completed by sixty-eight autistic participants and one hundred and four that were non-autistic. The findings revealed negative sexual experiences in approximately half of the autistic girls, and some of the autistic boys experienced various sexual dyadic behaviours. Compared to the non-autistic participants, there was an increased rate of limited sexual knowledge for the autistic participants. Although there is sufficient information in the existing literature concerning the connection between a lack of sexual knowledge and unsafe sexual practices and sexual victimisation, it is seldom studied regarding autistic people (Brown-Lavoie, Viecili and Weiss, 2014). A survey undertaken by the Terrence Higgins Trust (2016) highlight gaps in SRE which lacks appropriate information for young people leaving them susceptible to SAV. The Report is significant as it identifies that SRE is not comprehensively taught in the UK and is only mandatory in maintained secondary schools. The findings revealed it threatens a safeguarding crisis as one in seven individuals aged sixteen to twenty-four had not received SRE; three quarters of scholars were uneducated about consent; and at least 95% were uneducated on LGBTQIA+ relationships.

Davies et al. (2022) acknowledge the lack of appropriate training faced by those providing instruction whilst teaching young people with disabilities, particularly autistic children. This paucity of information and limited models available influence the way professionals work with autistic people. They are not equipped with the knowledge, training or resources to carry out this skilled work. Curtiss and Ebata (2016) undertook a study which examined how to train professionals in becoming sexual educators for the autism population highlighting that it is a much-understudied topic. Removing the barriers to learning in schools and acquiring knowledge from autistic people themselves to improve SE is fundamental whilst supporting them (Strnadová, Danker and Carter, 2022). Direct education is recommended for autistic adolescents and adults regarding their rights, consensual meaning, understanding of violence, and accessibility to information if they have been victimised with guidance to support services (Gibbs, Hudson and Pellicano, 2022). Mandy et al. (2022) state that there is significant variance in the age of receiving an autism diagnosis. Therefore, it is important to consider the proportion of school aged children who are undiagnosed and arguably, autism-friendly SE should be built into mainstream education.

## **2.14 Summary**

The focus of this research was informed by the gaps in the literature regarding SAV within the autism population. An obvious gap is that studies undertaken on SAV does not tend to engage with survivors who have a particular disability. However, this study specifically focuses on autistic individuals. It adds to the much-neglected research evidence base emphasising that being autistic in itself can be traumatising. The symptoms of autism can heighten an individual's susceptibility to SAV and literature addressing autistic sexual vulnerability is lacking in current research. The literature

review highlighted the added barriers faced by autistic individuals in the disclosure process compared to those in the general population. This creates implications for healthcare professionals in aiding the recovery treatment because of the complexities and convergences of autism, SAV, mental health, trauma, and PTSD which is also a neglected area of research.

The grey literature was valuable as it afforded the lived experiences of SAV of autistic bloggers which was missing in the empirical literature. Strikingly, it highlighted that receiving an autism diagnosis in adulthood had implications for autistic sexual vulnerability and self-identity, which set the individuals on a journey of self-discovery. The implications are that they had lived a life of uncertainty and struggled to understand themselves. Receiving an autism diagnosis helped them to process their experiences and it gave them a sense of identity. The phenomenon of the bloggers was significant as they exposed first-hand autistic male experiences of SAV which is missing in the empirical literature. Each of the individual narratives were poignant as they exuded emotion bringing the reality of their phenomenon to life. In contrast to some researchers who do not include vulnerable and marginalised participants in research, the bloggers' contributions provided much awareness of their experiences. They identified the value of being able to express themselves through writing. Equally important, the bloggers were thankful to be able to read the experiences of other autistic individuals as it gave them the encouragement to express their feelings via creative means of communication. They learnt from each other's experiences and it gave them comfort. It made them feel that they had worth and they felt less isolated by having a community that understood each other's experiences.

The literature reviewed in this chapter informed the research questions as it gave me a comprehensive understanding of the research topics pertinent to the implications of SAV within the autism population. Essentially, it identified what had been written on the subject under discussion, but it also highlighted inconsistencies in current knowledge in this under-researched phenomenon. The areas of interest that are specified in this chapter are of relevance as they help to bridge the gaps in the empirical literature. Furthermore, the literature review laid the foundations for the main arguments core to the research questions, building a scaffold that would acquire relevant information to answer them. I updated the literature review to capture novel research in the pursuit of relevant information to improve the research questions to make them concise. The following research questions frame the study:

1. How do autistic individuals make sense of their lived experiences of SAV?
2. How does being autistic increase sexuality vulnerability?
3. What are the implications for policy, practice and support?

The next chapter addresses the steps I undertook to answer the research questions.

## **CHAPTER 3**

### **METHODOLOGY**

#### **3.1 Introduction**

In this chapter I detail the appropriate steps undertaken within the methodological process to effectively answer the research questions. It begins with a discussion of sensitive research followed by emotion work in light of sensitive research, and emotion work theory. I give an account of my positionality statement articulating my identities including race, gender, class, sexuality, religion, personal experiences and privileges, as they influence the research questions and methods. This chapter provides a rationale for the choice of an IPA approach and its philosophical and theoretical perspectives. A description of the stakeholder meetings and pilot is provided demonstrating how it influenced the main research process. Sampling and the recruitment process are discussed including the inclusion and exclusion criteria. Ethical considerations are discussed for conducting complex and sensitive research with vulnerable individuals enabling the safety of the researcher and participants. The research design including the interview schedule and research questions, methods of data collection, semi-structured interviewing, rapport building, and data analysis are discussed. The trustworthiness and reliability of the research process and findings are demonstrated. This chapter concludes with a summary of the methodological procedure.

The purpose of this research was to obtain knowledge of the implications of SAV within the autism population to enhance awareness and prevention of autistic SAV. A reminder of the 3 R's (Haynes, 2013) is useful to recognise, report and aid their

recovery. It was achieved by giving a voice to six autistic survivors. Their unique experiences served towards meeting the research aims and effectively answering the research questions through close interpretation of their lived experiences. This study was conducted within a qualitative framework with the intention of eliciting rich data from an unfamiliar phenomenon to determine how autistic individuals made sense of their subjective experiences of SAV. Reid, Flowers and Larkin (2005) advocate for IPA within research that lacks exploration; hence, it was well suited to this research.

### **3.2 Sensitive research**

The topic being discussed lends itself to an exploratory qualitative study. Exploratory studies are recognised as a useful methodological approach in the exploration of phenomenon that is lacking in research and tends to utilise primary data or secondary data (Rahmon, Osademe and Ononokpono, 2023). This research fell into the realms of sensitive and complex research, particularly as the participants were vulnerable. It addressed taboo and stigmatising subjects including autism; SAV; autism sexuality; and mental health which could resurface painful memories triggering complex trauma. Research is regarded as sensitive if it is private, stressful, or sacred, and emotional responses may transpire (Barnard, Gerber and McCosker, 2001). Although undertaking sensitive research can cause additional harm to participants; arguably, it could have detrimental effects by *not* conducting it (Becker-Blease and Freyd, 2006).

Barnard, Gerber and McCosker (2001) identify a gap in the literature associated with participation in research addressing sensitive matters including child abuse. The research evidence suggests that it is uncommon for participants to become distressed

when asked about abuse (Becker-Blease and Freyd, 2006; DePrince and Freyd, 2006; Newman, Risch and Kassam-Adams, 2006). Undertaking sensitive research can be a positive and cathartic experience for participants (Davies and Gannon, 2006). Decker et al. (2011) identify that participants who had experienced SAV reported how beneficial their participation had been, despite feeling distress because of remembering past experiences.

### **3.3 Emotion work in light of sensitive research**

I discovered the work of Campbell (2002) and it was a revelation as it epitomised the spirit of emotionality that I wanted to capture within this research. The preface alone captivated me. It stirred up many emotions enabling me to 'think' and 'feel' the pain of SAV that other literature had failed to do. The accounts that I had initially immersed myself into were distressing. One particular story that has never left me was of a young woman who was brutally attacked by a gang of men and they vaginally and anally raped her. Fireworks were inserted into her vagina and she was left to die. Unbelievably, she survived, but she felt that she would never recover psychologically and considered whether death would have been better. I read many accounts with the same severity but they lacked emotionality. Campbell (2002) highlighted that the existing literature portrayed SAV as objective, cold and lacked feeling. Undoubtedly, there is no warmth attached to SAV and it is important to emphasise its coldness and objectiveness, but it fails to capture the emotionality beyond the act itself. It prevents deeper insight into the full extent of the phenomenon adding to the gap in knowledge. Campbell (2002) effectively captured the reality of SAV by incorporating her emotions and those of her research team and participants into her research. In her book *Emotionally Involved*, Campbell (2002) exemplifies the power of emotionality by

interviewing her team. They explained how they were affected by interviewing rape victims and their emotions included anger, sadness, guilt, shame, fear, and a loss of innocence. Despite the negative emotions, they felt privileged that the participants narrated their stories. This instilled hope in them as the research would help to reduce the stigma associated to rape, and raise awareness to help future survivors. This added compassion and warmth to her study and I wanted to learn more about it. Detaching emotionality from academia could negatively impact the learning process by hindering knowledge that may be gained at a deeper level.

Campbell (2002) engaged in emotion work providing a true insight into what it is like to 'think' and 'feel' SAV. There was an emotional connection between the researchers and participants which is gleaned throughout her work. The emotionality captured the richness of each story bringing to life the full extent of their experiences. It represented the bigger picture of SAV highlighting its long-term effects. This was contrary to the general literature which offered a snap-shot view without expanding on the psychological implications. The aftermath can be greater than the act itself but it is rarely discussed in the literature, failing to give justice to the impact on the lives of survivors.

Introducing emotionality into research has been criticised due to speculation that emotions are an unreliable source of knowledge, and skew research findings due to researcher bias (Holland, 2007). However, emotionality in research has started to gain credibility in recent years, and it is a source of scientific knowledge impacting upon the way that we think and learn (Fenge et al., 2019; Immordino-Yang, 2015). Emotions are informative and shape the research evidence because if we do not feel, we do not think and if we do not think, we do not learn (Campbell, 2002). Emotions can influence

the need to act and they are an important element in social conflict, social movements, and social change (Hochschild, 1983). They give meaning to events, and without them those events would be mere facts.

Consideration needs to be given to how the barriers associated with SAV can be broken down to shift the way that it is portrayed in the literature and media. Arguably, its coldness and objectivity create a fear in people contributing towards society burying its head. Fear arises from the unknown and by providing a truthful and open dialogue will help to break down the secrecy and silence shrouding SAV. If done sympathetically, society may get beyond its fear. It is crucial to strike a balance between respecting the cold and objective way that it is portrayed, yet capture its emotionality and compassion. People may be more responsive to the literature if they were less fearful.

### **3.4 Emotion work theory**

Undertaking sensitive research evokes emotional and painful responses (Ritchie and Lewis, 2003) affecting the participants and researcher. However, initially I had not considered the extent of their value in research. Upon consideration, I applied emotion work theory because it is important data to be incorporated into research (Hoffman, 2007). In 1983, Arlie Hochschild developed emotion work theory in her study *The Managed Heart*. Much of her work involved how emotionality can be labour intensive within the workplace. Emotion work extends into other fields whereby emotionally charged topics are debated regarding emotionality as a useful form of knowledge. This theory has filtered into academia and emotion is a useful resource within the social sciences (Fenge et al., 2019). Researchers acknowledge the leading role that

emotions play in all areas of one's existence and arguably, they cannot be separated from research (Campbell, 2002; Hubbard, Backett-Milburn and Kemmer, 2001; Dickson-Swift et al., 2009; Rowling, 1999). Justice would not be given to those involved in the research if their emotions were excluded (Johnson, 2009). The emotionality of the researchers and participants promotes intellectual clarity (Blakely, 2007).

Emotionality lies at the intersection of the person and society, for all persons are joined to their societies through the self-feelings and emotions they feel and experience on a daily basis. This is the reason the study of emotionality must occupy a central place in all the human disciplines, for to be human is to be emotional. (Denzin, 1984, p. x)

Emotion work theory is defined as managing one's own feelings and those of others in social interactions (Cook and Berger, 2000). Thompson (1994) purports that emotion work theory lends itself to different individual personalities and social functioning, and are the key roles that emotive processes play in these differences. Yang and Chen (2021) acknowledge the pioneering work of Hochschild (1983) whereby she laid the foundation for the evolution of emotional labour theory. The theoretical frameworks regarding emotional labour are chiefly ascertained from emotional regulation theory and a beneficial guiding framework for emotional labour (Yang and Chen, 2021).

Emotion regulation consists of the extrinsic and intrinsic processes responsible for monitoring, evaluating, and modifying emotional reactions, especially their intensive and temporal features to accomplish one's goals. (Thompson, 1994, p. 27/28)

Hochschild (1979) asserts that emotion work is unpaid emotional work that takes place in one's private life, and that emotional labour is emotion work which is managing

human feeling. She defines emotional labour as “the management of feelings to create a publicly observable facial and bodily display [that is] sold for a wage” (Hochschild, 1983, p.7).

Emotion work theory is a framework enabling the understanding of researchers’ experiences during the research process (Dickson-Swift et al., 2009). I was immersed in emotive data spanning several years, and I experienced various emotions. These concurred with Campbell (2002) and her research team including loss of innocence, fear, sadness, despair and anger, to hopefulness, optimism, and happiness as survivors can recover. Despite controversial viewpoints regarding the exclusion of emotions from research (Holland, 2007), I deemed that not including them would not aid a holistic approach because they are an inherent part of being human.

Whilst undertaking sensitive research, inevitably emotional labour will be experienced by the researcher which shapes data analysis (Rogers-Shaw, Choi and Carr-Chellman, 2021). Incorporating my emotions and experiences into the research provided an epistemic tool. I gained deeper insight into the feelings of the participants whereby I gave meaning to the interpretations of their phenomenon (Johnson, 2009). Pietkiewicz and Smith (2012) advocate for the researcher to step as far as they can into the participants’ shoes. This fits well with the philosophy of emotion work as taking an empathetic stance is essential. Kim (2018) states that we would not be acting in the best interests of an individual if we did not own their pain because it would not be our concern.

Researcher self-reflection, knowledge and experience was fundamental within the interpretative process to gain a deeper understanding of the phenomenon under

discussion (Johnson, 2009). Emotionalization of reflexivity is not just theoretical, but an exploration regarding whether an individual utilises their emotions to influence themselves and their lives (Holmes, 2010). My reflexivity throughout the analytical process was instrumental (Larkin and Thomson, 2011) because it enabled the data collection and analysis to be strengthened (Puddephatt, Shaffir and Kleinknecht, 2009). I also engaged in emotional reflexivity as emotions are central to reflexive processes (Holmes, 2010), and essential for high-quality research (Gilbert, 2000). I reflected upon the participants' emotional reactions from my journal as they narrated their stories, and I considered my own emotions in response to them. Emotions are bodily actions or movements appearing in the face, voice, and behaviours which may be witnessed by others (Damasio, 2003). I interpreted the participants' body language and it informed me about 'what' and 'how' they were feeling. I considered their reactive emotions such as the short and long pauses within the interview process. The double hermeneutic cycle helped me to understand the participants trying to make sense of their lived experiences (Smith and Osborn, 2007b). This connection enabled us to generate the research findings together (Guba and Lincoln, 1994). Furthermore, some of the participants had an epiphany whereby they described processing and comprehending their phenomenon live within the interview.

Reflective practice can impact upon self-awareness and enhance a practitioner's professional development more deeply (Bolton and Delderfield, 2018; Fox and Allan, 2014). The engagement in reflexivity and journaling my thoughts was beneficial. During the analysis stage, I was affected by the trauma experienced by each participant. I too had repressed traumatic events that were undealt with impacting upon my ability to analyse the data, and I was forced to take a break. I was risking burnout which can be challenging for researchers who are emotionally affected by

their work (Dickson-Swift et al., 2007; Johnson, 2009). There are human costs involved with emotional labour such as burnout (Hochschild, 1983). It would have limited my ability to produce good-quality IPA; therefore, I distanced myself from my PhD. I purposely did not think about SAV for several weeks and I engaged in positive activities. This helped my recovery of exhaustion enabling me to effectively continue with the demands of the analytical process.

#### **Reflective box**

IPA respects the value attributed to researcher reflexivity enhancing the research process. At the outset of my PhD, I was not attuned to my authentic self and whilst engaging with reflexivity and reflective work, I set on a journey of self-discovery. Reflecting upon my personal experiences of autism was fundamental. I had experienced trauma in adulthood and I repressed it as I had normalised it. There was a synergy with my lived experiences and the participants, enabling me to empathise at a deeper level from their perspectives and relay it within the research findings. Initially, I had not anticipated that emotionality would stir a mix of thoughts, beliefs and emotions in myself that I had not previously recognised. Some of the participants made sense of their experiences as they narrated and reflected upon what they had experienced. Similarly, I engaged in reflexivity, and learning from my participants helped me to make sense of my trauma. It was emotionally challenging and at times, painful. However, it was a cathartic experience and this deep awareness was enlightening as I discovered my true authenticity. This insightfulness was poignant as I reconnected with my inner-self bringing knew knowledge regarding my identity.

### **3.5 My personal experience and emotionality**

Qualitative research is personal and therefore, the researcher has a vested interest in the subject matter inevitably shaping the research (Sword, 1999). The roles of the researcher and participants are interactively linked and the research findings are generated collaboratively (Guba and Lincoln, 1994). I expected that undertaking emotionally charged work would stimulate emotional responses by all concerned and the power of emotions cannot be over-emphasised. I included my emotions and those of the participants into the study as the collaboration of emotions and intellect informed the research evidence (Blakely, 2007). Recognising the researcher as an

active agent is central in the production of knowledge (Watts, 2008). Similarly, Johnson (2009) recognises the importance of the experiences of the researcher and their emotions within sensitive research as they offer invaluable insight into the research topic.

There is increasing interest of feminist thinkers who have sympathetically introduced the concept of their personal experiences of disability to inform the research evidence, enhancing the interpretation and sense making of the data (Kittay 2008; Piepmeier, Cantrell and Maggio, 2014). The emotions of the researcher are a natural part of inquiries, but are undeveloped as a resource of information for SAV against women (Blakely, 2007). Incorporating their emotions adds to the accuracy of the analysis, thus allowing for a rich and in-depth understanding on emotion-laden subjects (Blakely, 2007). A personal insight of emotionality regarding sensitive topics including disability, sexuality, and trauma enabled me to give a true reflection of the experiences of the participants. It aided a deeper understanding of the interpretation and analysis of the data. This concurs with the beliefs of other researchers who have undertaken sensitive research and view the concept of emotionality as an invaluable resource for gaining a deep understanding of the phenomenon (Campbell, 2002; Hubbard, Backett-Milburn and Kemmer, 2001; Mitchell and Irvine, 2008; Sword, 1999).

### **3.6 Participant emotionality within the research**

The crux of this research was to listen to the voices of autistic survivors. Autistic people may not be able to tell their story because of social and communication difficulties. This can be compounded by repressing memories and emotions, particularly when they have experienced trauma. The participants faced their repressed memories and

talked through their trauma which helped them to engage with their emotions. Recognising these issues were significant within the interview, enabling the participants to give a comprehensive account of their experiences. Understanding this from a research perspective was crucial regarding whether they would be able to tell their story. Communication difficulties as well as repression could have been contributing factors towards unsuccessful previous attempts of disclosure.

As the researcher and interviewer, I utilised my interpersonal skills. Via active listening, and at times silence, enabled the participants to tell their story. Silence is an emotional response and there were times when it spoke volumes, and it was a powerful mode of communication and crucial within the analysis. This transpired whilst immersing myself into listening to the audio-recordings. The absence of speech enabled the participants to reflect in a space that they did not feel pressurised to speak. The words of Albert Einstein resonated with me:

I think 99 times and find nothing. I stop thinking, swim in silence,  
and the truth comes to me. (Bhatta, 2022, no pagination)

Some participants made sense of their experiences live, and exemplative of the double hermeneutic cycle. This contributed towards a deeper understanding of their phenomenon enabling me to gain an in-depth and nuanced interpretation of the data. The participants spoke about their difficulties in expressing emotions, but at times they surprised themselves as they effectively managed to do so. Talking through their trauma with me who is not a therapist allowed their narrative to positively unfold, corresponding with them needing just one person to informally tell their story to.

Each participant presented a range of emotions during the interview which were raw at times comprising sadness, sobbing, crying, anger, fear, horror, disgust, fearfully surprised, anxiety, awkwardness, confusion, happiness, laughter, amusement, happily surprised, hope, relief, silence, and calmness. I observed their body language and witnessing, understanding, and interpreting emotional reactions to non-verbal communication were pertinent because it contributed towards the interpretation of the data. Their body language included facial expressions, eye contact, stimming, crossed arms, head in hands, rubbing eyes, trembling, sighing, yawning, lip-biting, nodding, tone of voice, and smiling. The interview was not a counselling session but I utilised my counselling skills, particularly whilst some of the participants demonstrated that they were distressed. Blakely (2007) advocates for researchers to be receptive to their own emotionality as well as the participants, and that emotions are reconceptualised as an epistemic tool and data source to be incorporated into the research.

### **3.7 My positionality statement**

In sensitive research, positionality engages the way researchers have a clear meaning of their roles and boundaries within the researcher and participant relationship (Fenge et al., 2019). The question of positionality in a work of this nature was almost by definition problematic due to its complexity. My role as the researcher, interviewer, transcriber and analyst, positioned me as the main instrument to collect and interpret the data reflecting the reality-phenomenon of each participant. I established my position as a white, middle class, British, heterosexual woman in my mid-fifties. I have witnessed the movement of societal attitudes during the last five decades regarding topics considered controversial including premarital sex, contraception, illegitimacy, abortion, masturbation, sexuality, and LGBTQIA+.

As the mother of an autistic man, I have experienced the challenges faced by sexuality for people with disabilities. Outdated beliefs that they are not sexual beings are controversial as they can, and do, enjoy healthy sexual relationships (Haynes, 2013). As a parent of four children, I had open discussions around sex and sexuality which was different to my exposure as a child. Foucault (1976), through his detailed analysis of historical sexuality causes one to reassess their own assumptions about sex. I reflected upon my beliefs of sex from a young person until present day, and considered how it had defined me.

My religious background influenced my perception of sexuality. Catholicism was significant during my upbringing and sex was taboo. Catholic beliefs were enforced and I initially shared the 'Catholic guilt' that sex was a dirty act. Attending a strict Roman Catholic school reinforced those traditional principles. My education was embedded within a mindset that fornication was for procreation purposes only, and premarital sex was deemed sinful. Catholicism perceives masturbation as a mortal sin and not conducive to one's health. That assumption defies nature's way of releasing sexual feelings. Masturbation is the most frequently used sexual behaviour by autistic individuals not wanting to engage in sexual contact, and when a sexual relationship is unrealistic (Aston, 2001; Boucher, 2009). Catholicism condemns the use of contraception and opposed to condoms assuming that abstinence prevents the transmission of acquired immunodeficiency syndrome (AIDS).

I believe Catholicism instilled fear in children and abstinence was a course of action to being a good Catholic child. In Latin, *peccatum mortale*, a mortal sin, serves towards one's damnation if it goes unrepented before death. Despite the severity of a mortal

sin, it can be forgiven with repentance which is definitive for forgiveness and absolution. There is hypocrisy within the Catholic church and CSA is prevalent. Clergy, bishops and priests are amongst the perpetrators. As CSA is categorised as a mortal sin, The Archbishops Council (2017) question the extent of the deception of the doctrine as it has failed the church in preventing and responding to abuse. An example of this is the incorrect opposition between forgiveness and justice.

Sex was a taboo subject at home, and the irony was that the secrecy behind it sparked an interest which led me to early experimentation. The core values of sexuality were instilled within me from a religious educational perspective, yet the majority of SE was informed by friendship groups in the playground. Although many of the stories were embellished, it highlighted the sexual discourse between peers, and possibly the resistance to Catholic guilt when masturbation and sexual intercourse seemed predominantly high.

I have been inspired by the courage of my best friend. I met him when we were aged twelve whilst at school. He struggled with his sexuality because of the influence of his mother's devotion to Catholicism, and his father's homophobia. He led an unauthentic life of heterosexuality until his late thirties. We recently discussed our Catholic upbringing and how it defined us as adults and how our beliefs, values and attitudes have impacted upon our children who were given the freedom of choice regarding their sexual beliefs.

There was a synergy between my experiences and the participants, which inadvertently put us in similar positions. By exploring their traumatic stories, I

developed a deeper understanding of my sexual identity that was influenced by my environment. I had lacked autonomy, and I was unable to put up a resistance to those in positions of power and trust. I do not intend to berate Catholicism as some values are instilled in me today, but they became normalised and I conformed. I respected my elders and I obeyed their instructions despite feeling confusion. Attending Mass every Sunday was not a choice but an expectation. It feels that it was a form of conditioning as I was exposed to an environment whereby the views of others were imposed upon me. It was confusing when the priest preached in Latin; a language I do not understand.

My position as a researcher takes the form of multiple roles and it is fluid in how they are relevant to conducting the research (Fenge et al., 2019). My changing positionality is unsurprising, mainly because undertaking this Doctor of Philosophy (PhD) set me on a journey involving several years of soul-searching. I considered my participants' positionality within this research because I am non-autistic, and I had positioned myself within a phenomenon that I have not personally experienced. However, SAV is an area that I have significant experience due to my previous careers in education, child protection, and mentoring which provided me with the solid foundations for this research.

I reflected on the nature of SAV and the impact of trauma, and the highly individualised presentation of my participants. A primary area of self-reflection was around societal attitudes towards SAV, and sexuality concerning disabled people. Whilst these areas are taboo, my position is one whereby open discourse and distancing from value judgements can be achieved. Even within modern-day society there remains

controversy around SE which has been influenced by the principles of dissimilar religions and cultures. Outdated concepts regarding SE and people with LDs have previously disregarded their sexuality needs due to believing they do not experience sexual attraction, are asexual, or unaware of their sexuality (Konstantareas and Lunsky, 1997; Sullivan and Caterino, 2008). As the parent of an autistic son, I have considered my attitudes towards sexuality and disability. Although I would like my son to engage in healthy sexual relationships; this is unlikely. I have addressed concerns around his vulnerability and to my knowledge he has not experienced SAV.

I considered my position as a mother, particularly as the average age of the participants were similar to my children. I was mindful not to let my instinctual nurturing way 'mother' them. Setting clear boundaries whilst undertaking sensitive research was important ensuring that the interview did not become a therapy session (Fenge et al., 2019). Many years of parenting, and mentoring autistic individuals put myself and the participants on a similar level enabling them to feel at ease. I reflected upon the challenges I faced whilst fighting the system to receive an autism diagnosis for my son, and I considered the difficulties that my participants experienced in receiving a late diagnosis.

Regarding my philosophical position, comparisons were drawn from the work of Foucault (1976) who, by exploring sexual morals and ethics through history, created a thought process whereby one is asked to reassess their own beliefs and morals around the sexual act. By highlighting for example, the fluidity of dominance and submission in ancient Greek relationships between men and boys, and discussing the naturally submissive roles of women and slaves, Foucault intersects with the current

work. Particularly, the emotional consequences of SAV regarding the victim's feelings of submission and humiliation, and the tendency to self-blame. There is intersectionality of SAV with autistic people and the way they process traumatic experiences that matches closely with Foucault's discourses around submission, and the positive schema focused on male domination and penetration. This raised important issues about empathy and experience regarding knowledge about a topic. I reassessed my beliefs and morals concerning my sexual experiences around consent and sexual preferences. This led to deeper awareness of the complexity of sexuality per se and of autistic sexuality. I have reconciled my thoughts comprising the age of consent, sexual preference, sexual ideation and paraphilic sexual desires which is more nuanced than I had previously considered. Questions raised by the current work around autism and SAV, create more intricate lines of enquiry into what constitutes healthy sexual activity.

Hopefully, my positionality statement has given the reader an awareness of how this research was influenced by my personal experiences, values, attitudes and social background. My positionality helped to shape my methodology which is now discussed.

### **3.8 Methodology and methods**

Methodology is concerned with the principles guiding the way research is undertaken and asks the question "how can the inquirer go about finding out whatever they believe can be known"? (Guba and Lincoln, 1994, p. 108). Research methods are the tools whereby data are collected and analysed (Crotty, 1998) and they can be qualitative or

quantitative. This research employed qualitative methodology underpinned by interpretivist epistemology and related to subjectivism based on real world phenomena. I explored phenomena from the perspective of each participant to gain insight into the emotions associated with the human experience; the objective was to draw out the richness of individual experience. A quantitative approach would have been less effective because individual experience would be limited to certain pre-determined response categories with little real-world authenticity lacking the descriptive richness and lived experience (Kvale, 1996).

### **3.9 The rationale for an interpretative phenomenological approach**

Consideration was given to which qualitative research paradigm would be suitable. I selected IPA to elicit sensitive phenomena. The stakeholder meetings informed the methodological process ensuring the research questions were answered. This was achieved by utilising a phenomenological research design because it was qualitative to gain an in-depth exploration of personal experiences (Smith and Osborn, 2015). This research intended to advance knowledge through the experiences of autistic survivors of SAV to bridge the gap in research. As phenomenology is concerned with the human experience (Patton, 2002), it was a well-suited design which enabled the participants to tell their narrative in their own words. It allowed me to capture first-hand their thoughts and feelings to produce in-depth descriptions of an unknown phenomenon.

Purposive sampling, sample size, semi-structured interviewing for data collection and analysis were relevant in justifying IPA. IPA gravitates towards recruiting purposive samples of participants because they share particular experiences (Smith, Flowers

and Larkin, 2009). It was participant orientated and its flexibility allowed me to get to each of their experiences (Alase, 2017). The sample size for IPA is concerned with quality and not quantity, and because human phenomenon is complex, it is beneficial to concentrate on a small number of cases to gain detailed perspectives (Smith, Flowers and Larkin, 2009). IPA interviews intend for the researcher and participant to develop a relationship enabling the lived experience to be explored and analysed (Alase, 2017). This study focus fitted well with an exploratory research design and a phenomenological approach was an appropriate method, since its exploratory nature enabled me to collect data which was under-researched (Liamputtong and Ezzy, 2005).

“A phenomenological research is well suited for studying affective, emotional, and often intense human experiences” (Merriam, 2009, p. 26). It was conversational and permitted the participant to steer the course of the interview. IPA is phenomenological because it gains personal insight into individual phenomenon compared to producing an objective record of a situation (Biggerstaff and Thompson, 2008). This research did not test hypotheses. The inductive nature of qualitative methodology is concerned with the theory derived from the data compared to deductive reasoning that tests existing theories. The research objective was to determine how these individuals had been affected by SAV, and it was exploratory to gain insight into their experiences. It was a retrospective process and it was interesting to look back on a single phenomenon to see what was going on in each case.

In conjunction with IPA, I incorporated emotion work theory and I included my personal experiences and emotions into the research process. Arguably, this could be

considered contradictory to the philosophical underpinnings of phenomenology as it is assumed that the researcher brackets preconceived assumptions.

Dörfler and Stierand (2020) state:

...bracketing can be conceptualised as the researcher's attempt to hold in abeyance their pre-understandings and assumptions to attain experiences before making sense of them (p. 2).

Although Thomas and Sohn (2023) purport that bracketing, also referred to as 'epoch', is important in the philosophy of phenomenology, some phenomenologists debate whether descriptive and hermeneutic approaches to bracketing are necessary. There is inconsistency within the historical and philosophical underpinnings of bracketing, and its nonuniformity has initiated tensions due to the introduction of the phenomenological reduction by Husserl (Tufford and Newman, 2012). Neubauer, Witkop, and Varpio (2019) acknowledge that modern philosophers struggle to contend with Husserl's perceptions of bracketing. Heidegger rejected the notion of reduction (Tufford and Newman, 2012). He maintained that the conscious experience of phenomenon in an individual is by no means separate from their world or personal history (Neubauer, Witkop and Varpio, 2019). Within hermeneutic phenomenology, the researcher cannot eliminate their *lifeworld*, and the researcher's prior experiences and knowledge add value to the inquiry (Neubauer, Witkop and Varpio, 2019). This sat well within emotion work as it is expected that the researcher includes their personal experiences and emotions, hence the rationale for the adoption of a more Heideggerian phenomenology.

### **3.10 Ontology and epistemology in IPA**

Ontology is the study of the nature of reality (Hudson and Ozanne, 1988). Crotty (1998) states that epistemology is the philosophy of knowledge “how we know what we know” (p. 8). Epistemology is rooted within philosophy and it is concerned with the theory of knowledge attempting to answer the question “How, and what, can we know?” (Willig, 2008, p. 2). The two primary ontological and epistemological stances are positivism and interpretivism that have an objectivist epistemology serving towards various methodological approaches (Tuli, 2010). The position of interpretivism regarding ontology and epistemology is that interpretivists deem that reality is multiple and relative (Hudson and Ozanne, 1988). These multiple realities depend on other references systems for meanings making it difficult to interpret regarding fixed realities (Lincoln and Guba, 1985). Interpretative research is committed to understanding and interpreting the meanings in human behaviour as opposed to generalisation and the prediction of cause and effects (Neuman, 2000).

### **3.11 Philosophical and theoretical perspectives of IPA**

IPA is a subjectivist epistemology and its interpretative nature makes it possible for the researcher to access the cognitive inner world of an individual; thus, enabling in-depth interpretation of the data because of close interaction between the researcher and participant (Biggerstaff and Thompson, 2008). The main aim of employing a phenomenological philosophy is to gain an understanding of an individual’s perceptions and their meanings within the world in which they live (Langdrige, 2007). To obtain the participants’ lived experiences of SAV, it was important to be familiar with the three concepts of IPA:

...interpretative phenomenological analysis is an approach to qualitative, experiential and psychological research which has been informed by concepts and debates from three key areas of the philosophy of knowledge: phenomenology, hermeneutics and idiography. (Smith, Flowers and Larkin, 2009, p. 11)

### **3.12 Phenomenology**

Langdrige (2007) defines phenomenology as the “study of human experience and the way in which things are perceived as they appear to consciousness” (p. 10). IPA is phenomenological as it proposes to explore and capture an individual’s lived experience (Smith, 2004). Smith, Flowers and Larkin (2009) have been influenced by the work of Husserl, Heidegger, Merleau-Ponty and Sartre, considered to be four of the major philosophers within the phenomenological paradigm. Edmund Husserl, a philosopher and not a psychologist, has been described as the founder of the phenomenological approach that endeavours to find a meaning for a person to understand their *own* experience of their phenomenon (Smith, Flowers and Larkin, 2009), and regarded as “transcendental phenomenology” (Larkin, Eatough and Osborn, 2011, p. 5).

### **3.13 Hermeneutics**

Phenomenological approaches have evolved and with the initiation of Heidegger who was a student of Husserl, there was a movement towards a more existential turn to gain a better understanding of existence. It was further developed by Sartre and Merleau-Ponty before moving towards hermeneutics with the work of Gadamer and Ricoeur. IPA is interpretative and informed by hermeneutics. Langdrige (2007) defines this as the theory of interpretation encompassing “the restoration of meaning” (Ricoeur, 1970, p. 8).

Understanding our own assumptions and prejudices is important regarding the phenomenon under discussion before interpreting the experiences of participants. This provides transparency during the data collection and analysis as it is unlikely that it will bias the research findings as the researcher lays bare their preconceptions. This is a reflexive process strictly adhering to the paradigm of IPA. Reflexivity is an all-important element at each phase of the research despite it being complex work within experiential qualitative research (Shaw, 2010). Self-reflection, knowledge, and experience are deep rooted in the research process which is fundamental to the interpretative process, and the researcher's emotions relate to the phenomenon being researched (Johnson, 2009). The engagement of reflexivity enables the researcher to navigate the participant's stories. The distinctiveness of IPA analysis is the foregrounding of participants' interpretations (Smith, Flowers and Larkin, 2009). The researcher's active role necessitates a double hermeneutic whereby "the participant is trying to make sense of their personal and social world; the researcher is trying to make sense of the participant trying to make sense of their personal and social world" (Smith, 2004, p. 40).

### **3.14 Idiography**

IPA takes an idiographic stance with a commitment to the detailed analysis of the phenomenon under investigation (Eatough and Smith, 2006). IPA's idiographic bearing is explicit in the examination of each detailed case before moving on to general claims (Smith and Osborn, 2015). The detailed immersion with each individual case whereby insights are produced can only be an idiographic approach within IPA analysis (Willig, 2008).

There was a broad body of literature addressing SAV that may be considered to be nomothetic regarding its generalisation within the wider population. The research evidence was collected quantitatively and was objective because it had been statistically quantified. In contrast, although IPA does not deliberately set out to avoid making generalisations, it is more concerned with rich and detailed individualised experiences (Smith, Flowers and Larkin, 2009). Rather than being concerned with causal relationships, it is committed to the quality of personal experience (Pietkiewicz and Smith, 2012).

### **3.15 Evaluation of the methodological approach**

I evaluated the methodological approach and was satisfied that IPA was suitable to fulfil the research aims. Six autistic survivors voiced their experiences, and each narrative offered a personal insight into their experiences which added to the research evidence. The stakeholder meetings and pilot which is discussed below influenced the choice of a phenomenological methodology to effectively answer the research questions.

### **3.16 Chosen methods and rationale for the stakeholder meetings and pilot**

Boaz et al. (2018) suggest that stakeholder engagement practices have increased, and researchers utilise them to achieve impact in research as stakeholders may play a key role. I conducted two stakeholder meetings utilising semi-structured interviews. They are flexible and conversational with a purpose, allowing the researcher to explore the 'insider perspective' and to capture first-hand opinions, feelings, perceptions and experiences of participants (Burns and Grove, 2005). I undertook a focus group

comprising an autism specialist, specialist mental health mentor and counsellor, disability advisor and a student's union representative. I also conducted a semi-structured interview with an Independent Sexual Violence Advisor (ISVA). Focus groups and semi-structured interviews are associated with interpretive perspectives and produce qualitative data (Dewi, 2021). They offer similar strengths as they produce deeper information compared to secondary data. Semi-structured interviewing and focus groups have similar limitations as they consist of small sample sizes which limits generalising the findings (Adams and Cox, 2008). Adversaries to this approach often believe that reliability and validity cannot be achieved through reduced sample sizes, and the results may be biased due to researcher immersion into the field. I did not expect to generalise the findings as the experience of SAV was unique for each participant. IPA can be extremely time consuming, and is not systematically theorized (Pietkiewicz and Smith, 2012). This research was self-validating and the evidence was reinforced by the thick description produced from the data.

Focus groups and semi-structured interviews differ in their methods. A focus group involves interviewing several participants simultaneously. It is the only method offering interaction between participants initiating a dialogue of diverse opinions and experiences (Robson, 2011). Contrastingly, semi-structured interviews attain specific opinions, feelings and experiences from the participants perspective and they are more in-depth than a focus group. Focus group methodology produces clear ethical challenges in comparison to one-to-one interviews (Sim and Waterfield, 2019). Confidentiality is easier to manage with one individual whereas information is shared with other participants in focus groups. The researcher has limited control regarding

what the participants discuss outside of a focus group and therefore, confidentiality may be difficult to manage (Sim and Waterfield, 2019). To address this issue each participant signed a confidentiality form stating that anything discussed within the meeting would not be shared outside of the group. I debriefed the stakeholders at the outset of the interview about respecting each other's opinions, particularly as the topic under discussion was sensitive. I also reiterated this during the interview and upon its closure.

In addition to the stakeholder meetings and single semi-structured interview, I conducted a pilot which is recommended prior to undertaking the main research. It helped to establish its feasibility and to enable the refinement of the research approach (Robson, 2011). The pilot for the main research was Daisy and she was also the first participant. I conducted a semi-structured interview with her and it produced very rich data. Subsequently, it was agreed with Daisy and my supervisors that her data could be used within the main body of the research. For her interview, Daisy was accompanied by my colleague who introduced her to my research. This raised an ethical dilemma regarding confidentiality as they knew each other. We all had an informal discussion regarding her role as the pilot and we discussed protecting her personal information. Daisy disclosed that she had detailed her experiences of SAV to my colleague. He worked in the mental health sector and understood the limits of confidentiality. Daisy informed me of their trusting relationship and valued his discretion. She explained that she understood the worth of this research and her willingness to participate was evident.

The stakeholder meetings and the pilot were advantageous as they produced rich data which helped to inform the development of the interview schedule. Several themes emerged from the focus group data analysis (see Appendix I). They highlighted gaps in research pertinent to autistic SAV, and autistic sexual vulnerability. Subsequently, my attentiveness to these findings influenced the creation of the research questions to help to bridge the gap in research.

### **3.17 Reflection**

For responsible and ethical practice to take place, reflective and reflexive processes are essential (Bolton, 2010). I reflected upon the stakeholder meetings which highlighted some adaptations for the main research including testing the interview questions. For example, the first question was unsuitable as it was closed: “Have you worked with anyone that has disclosed that they have been sexually abused?” Although I probed to elicit the required information, an open and more welcoming question would have been better suited to put the participants at ease. This was a good lesson and in the subsequent interviews I was mindful of open-ended questioning.

The stakeholder meetings and the pilot were effective as they established that the research was feasible and perceived as interesting by those involved. It validated the research question and confirmed the research gap originating the study. It made a valuable contribution towards the development of the main study. As I was exposed to first-hand knowledge, I gained valuable insight into the phenomenon of SAV and it influenced the creation of an initial set of categories guiding the next steps of the research process.

The stakeholder meetings and the pilot provided implications for narrowing the research and adjusting the sampling criteria. Initially, I had intended to include a focus group comprising six professionals; six interviews with autistic survivors; and four interviews with parents/carers. Despite the stakeholder meetings and the pilot being a scaled down exploration of the main study, a copious supply of data was collected, emphasising that the sampling criteria was unpractical. Subsequently, I amended it and I chose semi-structured interviews consisting of six autistic participants. This was compatible with the initial research question which set out to listen to the voices of autistic individuals. The stakeholder meetings gave valuable insight into SAV from the professional perspective, and vital in building the foundations for the main research regarding practicalities; interviewing techniques; and support needs.

The pilot was fundamental for several reasons. Daisy gave feedback on my interview technique and the proposed research questions. This was advantageous because it confirmed that my interviewing style conformed with IPA as I allowed Daisy to tell her story in her own words. My verbal input was minimal to encourage her to talk at length (Smith, Flowers and Larkin, 2009). She referred to the rapport building and my approachability and she felt comfortable within my company. Daisy detailed her experiences because I did not have any shock reactions to the explicit content of her story. She confirmed that the interview questions were suitable and flexible. They were asked in a way that allowed her to be open within a situation that had previously closed her down whilst disclosing SAV (see Appendix I for further discussion and the results of the stakeholder meetings and pilot).

The stakeholder meetings and the pilot were constructive as they achieved its main aim of refining the feasibility of the study, and highlighted modifications for the main research. Although I had considered the sensitivity of the research, I did not account for the emotional responses of the stakeholders. Similarly, I underestimated my reactions to the data and I was surprised by how it affected my emotional state. I did not anticipate the detailed disclosure by the ISVA who experienced CSA. Also, another participant explained that her daughter was a SAV survivor. This raised three important factors. Firstly, expect the unexpected whilst interviewing. Secondly, do not underestimate the significance of emotionality within the research process. Thirdly, recognising the importance of the safety needs of all involved in the study is crucial.

Whilst conducting complex research, I expected it to provoke emotional reactions. During the initial stages of my PhD, I immersed myself into the literature of SAV to become more knowledgeable about the distressing effects it has for the participants and researcher. Although the text-book knowledge was beneficial from an academic perspective, it did not prepare me for the emotionally disturbing disclosures that emerged within the preliminary stages of data collection. The stakeholder meetings and pilot highlighted strategies to manage my psychological well-being. Sensitive research requires preparation, and supervision is essential enabling the researcher to minimise their physical and emotional risk (Dickson-Swift et al., 2006; Tuffrey-Wijne, Bernal and Hollins, 2008; Woodby et al., 2011). I implemented self-care and made connections with support services including counselling, supervision, de-briefing, and I had close friends who were available if I required their support.

### **3.18 IPA and sampling**

In line with the theoretical underpinnings of IPA, the selection of participants was based upon accessing a specific perspective on the phenomena being studied; hence, they represent a perspective as opposed to a population (Smith, Flowers and Larkin, 2009). This approach was well suited to meet the aims of this research, and purposive sampling was employed as opposed to random sampling as the participants were chosen from the autistic population. The purpose was to gain an in-depth understanding into phenomena which only those with specific knowledge have (Bluff, 2005). The participants for this research were representative of a homogeneous sample, enabling a distinct group of individuals to have their voices heard.

### **3.19 IPA sample size**

A recommendation of six to eight participants is suitable for doctoral programmes that employ IPA as the amount of data collected is not overwhelming, yet sufficient enough to examine the similarities and differences between the individuals (Turpin et al., 1997). The sample size recommended for an IPA study is inconclusive, but four to ten interviews is adequate for students embarking upon a professional doctorate (Smith, Flowers and Larkin, 2009). I opted for a sample size of six participants to fulfil the research purposes in the idiographic approach. Hefferon and Gil-Rodriguez (2011) state “more is not always more” (p. 757). Smith, Flowers and Larkin (2009) explain “The issue is quality, not quantity and given the complexity of most human phenomena, IPA studies usually benefit from a concentrated focus on a small number of cases” (p. 51).

### **3.20 IPA and autistic participants**

Hughes (2019) advocates not only giving a voice to participants whose voices are seldom heard, but giving them a sense of empowerment. Instead of excluding marginalised individuals from research participation, my intention was to listen to their voices and give them visibility. It gave them a form of control which had been taken away by their abusers. Howard, Katsos and Gibson (2019) acknowledge limited research that is representative of the perspectives and experiences of autistic participants within qualitative research. Encouraging their participation and engaging with their perceptions can enhance the knowledge base of autism research lacking within the literature.

Including autistic participants in research could be problematic due to their use and understanding of language (Dewinter et al., 2017). Willig (2013) states that to capture the experience of participants, there is an emphasis on the use of language as a mode of expression which may be challenging within IPA. A study conducted by Dewinter et al. (2017) who interviewed eight autistic participants found that the reliance upon spoken language could be a barrier in collecting rich data due to limited expressive language, extensive use of formal language, and using complex and expressive words. Arguably, IPA is an ineffective approach to elicit phenomenon from autistic individuals and those with communication difficulties. However, MacLeod (2019) attests to the effectiveness of IPA as a research approach for consulting with autistic individuals.

Consideration deserves to be given to creative ways of engaging with autistic participants by utilising resources including visual support (Dewinter et al., 2017),

photo-elicitation (King, Williams and Gleeson, 2017), and/or participant diaries and drawings (Adams and Stephenson, 2016). This enables them to have an inclusive role within research. The commitment of IPA concerning an equality of voice and the reflexivity of the researcher may reveal the autistic individuals' experiences (Howard, Katsos and Gibson, 2019). There has been an increase of IPA research incorporating the autistic voice giving credibility pertinent to sexual orientation which has been addressed within IPA studies (Cridland et al., 2014; Dewinter et al., 2017; Howard, Katsos and Gibson, 2019).

Non-verbal communication can be a powerful medium whilst sharing information. I considered the language barriers that could hinder the interview process including the participant's literal interpretations; inability to effectively express themselves; echolalia; and delayed responses due to processing information. Therefore, alternative methods of communication were offered. The information sheet (see Appendix II) acknowledged that the participants might have difficulty in telling their story and that I would support their preferred mode of communication. Creative options were offered to help them express themselves, but spoken language was favoured by each participant.

A key aspect of IPA research is to gain experiential knowledge from the participant (Larkin, Watts and Clifton, 2006). "Here the participant has experiential expertise and is the sole focus of your attention" (Smith, Flowers and Larkin, 2009, p. 64). To access the participants' experiential worlds, it is important to recognise the skills of the interviewer to capture their unique experiences. IPA is dynamic because the researcher plays an active role during the interview (Smith and Osborn, 2007a) and is

a “conversation with a purpose” (Smith, Flowers and Larkin, 2009, p. 57). This is helpful in collecting complex and emotional-laden data enabling the participant to narrate their experiences thoroughly, combined with empathetic engagement into interesting aspects (Smith and Osborn, 2015).

### **3.21 Recruitment process**

Accessing participants through gatekeepers protects the research sample (DeJonckheere and Vaughn, 2019). Due to the complexity of this research and the participation of autistic individuals, it was vital to ensure that their safety needs were met. This was aided by Victim Support which I was acquainted with at the outset of this research. A particular caseworker was interested in my study, and similarly, I was inspired by their work with survivors of SAV. We agreed that support services for the autism population were fragmented, and there was a need for joined up services to meet their needs.

As discussed and agreed with my supervisors, Victim Support were ideally positioned to act as the gatekeepers, and this was confirmed by the Research Ethics Committee (REC). They were confident that there would be an interest in the research with a sufficient number of participants coming forward. Victim Support have a data base whereby some clients agree to being contacted for research purposes once their support has finished. These clients were approached in accordance to the protocols in which they agreed, and it would be their choice to participate. No participants responded and I was conscious of time limitations. Following a discussion with a professional colleague, he informed me of a close acquaintance who was an autistic female survivor of SAV. She was interested in my research and he informed her that

I was in the recruitment process. Subsequently, she put herself forward as a potential candidate. To ensure that she was not coerced to participate, she was guided to Victim Support to offer her interest in the study. Protocol was strictly adhered to and she met the inclusion criteria as follows:

Inclusion criteria:

- Victim-survivors of SAV with a formal autism diagnosis
- Above the age of eighteen
- Does not have a language impairment and has the ability to communicate using spoken language.

Exclusion criteria:

- Below the age of eighteen
- Additional learning difficulties
- Involvement in any police enquiries or legal proceedings regarding their SAV at the time of data collection.

Due to the lack of response from the recruitment process I considered alternative options. The second participant Elijah, was known to me as I had been his mentor. From the outset of my PhD, he was interested in my research. He disclosed that he was a survivor of SAV and showed a willingness to participate because he saw the value of the study. As I was struggling with the recruitment process, I discussed Elijah's enthusiasm with my supervisors. It was agreed that he could potentially make a valuable contribution. To ensure that he was not obligated to participate and to safeguard him from coercion, he was guided to Victim Support. It was confirmed that he was a suitable candidate and he too followed the protocol expected by Victim

Support. As Elijah had initially been signposted to Victim Support upon disclosure of SAV, my supervisors recommended that his caseworker be present in the interview to ensure that he was willing to participate without persuasion. This was discussed with Elijah and he decided that it would be beneficial to have him present.

Although I had two willing participants, the research sample was short of four; therefore, I had to reconsider the recruitment process. I had delivered a presentation on autistic SAV to university students and it evoked much interest. Immediately afterwards several students approached me indicating that they would like to participate in my research. They offered their contact details for future reference. I discussed this with my supervisors and they agreed that it would be appropriate ensuring that the same safeguards applied. I contacted them and they showed a willingness to participate. I guided them to Victim Support following the same protocol utilised by Daisy and Elijah. Four of them met the inclusion criteria and Victim Support acted as gatekeepers as originally planned.

Victim Support played an active role throughout this research and one particular colleague took the main lead as a gatekeeper. He ensured that the recruitment stage was seamless. He efficiently responded to the requests of the participants and sent an advanced package of information to each participant recruited including an information sheet (see Appendix II) and consent form (see Appendix III). Consideration was given to the interview location and I asked where each participant would like to be interviewed (Smith, Flowers and Larkin, 2009). All interviews were conducted in a neutral location preventing negative or positive links with a specific venue (Powell and Single, 1996). Victim Support were readily available throughout the interviews in the event of any unforeseen circumstances. The gatekeeper offered

sound advice and support to myself and my participants as required, and he was available for de-briefing. He was highly-trained and experienced within the field of SAV and trauma. Although there is a lack of knowledge regarding autism and SAV and the treatment of autistic survivors, the gatekeeper took into consideration their individual needs and responded accordingly.

### **3.22 Ethical approval**

The ethical approval process started in July 2016. After working exclusively on the application for an intensive eight months, I submitted a detailed justification as to why this research was vital. I identified risks and safety measures, and I offered a detailed account that ensured the safety of all involved. I awaited a response from the University of Birmingham's REC. They responded with numerous queries and this was the start of several months of dialogue. Ethical considerations were scrutinised which produced back and forth negotiation of the study. I rigorously defended my position as a researcher regarding integrity and commitment to the research and participants. I engaged with my supervisors and discussed issues pertinent to the safety of all involved. The REC recommended that I used secondary data as a less risky method of data collection. Undoubtedly, collecting secondary data would be inconducive to this research as it would not offer a true reflection of what I intended to achieve. The purpose of this research was to gain the autistic voice, and denying them would be akin to ableism. It could minimise their autonomy, particularly as this population is frequently marginalised and silenced within society. Advocating for their voice, I stated the case for applying IPA whereby participants are regarded as experiential experts. I intended to be actively involved to capture the essence of rich data, which would not be the case using secondary data. This approach would not remain true to the

philosophy of IPA whereby the participants are the experts on their experiences (Smith, Flowers and Larkin, 2009).

It was a painstaking seventeen months from the start of the ethical process through to gaining approval in November 2017. Although it turned out to be an unexpected and extensive piece of work, it stood me in good stead. It helped me to think divergently regarding the ethical considerations for this research which was important given the combination of sensitive research, emotionality, and the vulnerability of the participants.

### **3.23 Ethical considerations for this research**

Championing the voice of individuals who are frequently unheard is essential, particularly for those who advocate the need to be heard. I briefly describe the experience of Elijah in the following reflective box, thus highlighting the importance of ethical considerations in sensitive research.

#### **Reflective box**

I was Elijah's mentor at university and I was privy to his disclosure of SAV, triggered by the suicide of his autistic friend. Elijah was raped on two separate occasions by different men. Bondage, discipline, sadism, and masochism (BDSM) was a factor in his SAV. He is lucky to be alive because it nearly ended in fatality. He shared his innermost thoughts and I helped him to process them. I aided his recovery by accessing appropriate support services. Symptoms associated with autism impacted on all involved within the healing process. It highlighted the necessity for this piece of work to get the insider perspective directly from autistic individuals. He agreed that championing the voice of other victim-survivors is imperative to eradicate the stigma and secrecy surrounding SAV. By listening to their stories, society can be better educated. The knowledge gained will help to destroy the ammunition that parts of society hold in taking advantage of an underrepresented population.

Elijah's experience exemplified the sensitivity that needed to be implemented into the ethics whilst undertaking sensitive research with vulnerable participants. I did not shy away from it, particularly whilst discussing my prospective research with my students at the outset of this study. They showed an interest stating that it was valuable. The willingness of the individuals who disclosed SAV influenced my decision to conduct this study. Disabled and vulnerable individuals *do* want to participate in sensitive research, and those who are marginalised should not be excluded. If robust safety measures are implemented, it is unreasonable to consider that willing participants are excluded. If it is handled sensitively as highlighted in this research, they do make valuable contributions to knowledge. The fear of being ableist was a concern and the only way to understand how this population reacted was to ask them.

I addressed details of ethics to ensure that the participants were able to cope with revisiting their trauma. The topic being researched may be rare and in turn will define the boundaries of the sample relevant to the study (Smith, Flowers and Larkin, 2009). Any victim of crime could potentially be at risk of mental health issues. Autistic people may have mental health problems related to autism and they could be exacerbated by the experience of SAV. It was not viable to exclude those with mental health difficulties because it could skew the research findings. Working with autistic individuals with mental health problems was not outside my sphere of expertise, and appropriate support services and crisis counselling was available if required. The protocol employed by Victim Support meant that those with severe mental health difficulties would automatically be excluded. They follow an outcome model assessing the emotional stability of their clients and is used as an initial baseline. They can confirm the mental soundness of their clients and are able to highlight clients who they deem will be caused least distress.

Ethical issues can arise from the start of a study through to the dissemination of the findings (Holbrook, 1997). The planning of the safety protocol for this research was rigorous and strictly adhered to. Several researchers have highlighted the importance of the safety needs of *all* involved within sensitive research (Campbell, 2002; Fahie, 2014; Fenge et al., 2019) which has been lacking within literature. Robust ethical procedures were implemented to protect individuals involved in the research due to its complexity. The physiological and psychological safety of all individuals was fundamental and appropriate measures were implemented to minimise any risks identified (DoH, 2005).

There has been a positive shift for those considering undertaking sensitive research as the Gov.UK (2019) has produced a service manual with safety guidelines. It provides information concerning the well-being of the researcher and participant, particularly research including vulnerable individuals. Ethical consideration was given to the way this sensitive research was designed to safeguard quality and integrity enabling a valuable contribution to knowledge (Fahie, 2014). Ethics refers to conforming to a set of principles with an obligation to the commitment of the rights and respect of the participants, and protecting the researcher from litigation (Israel and Hay, 2006). Respect, sensitivity and tact are the principles of ethical attitudes (DeJonckheere and Vaughn, 2019). Within ethical codes of practice there is discussion concerning the researcher and participant, but the effects that the research has on the researcher is seldomly considered (Fenge et al., 2019).

Participants involved in sensitive research could be at emotional risk, but the impact it has on the researcher has only latterly been addressed (Mallon and Elliott, 2019).

There is limited literature addressing the impact on the researcher whilst undertaking complex research (Fenge et al., 2019). Researchers may become overwhelmed whilst interviewing and they may experience exhaustion (Dickson-Swift et al., 2009). They can be exposed to situations that are emotionally disturbing whilst conducting sensitive research or with marginalised groups, and it may be psychologically challenging during data collection and analysis (Fenge et al., 2019). The psychological well-being of the researcher can affect the participant. Therefore, it is essential that the safety needs of the researcher are addressed and appropriate measures implemented to minimise risk. For researchers who are considering undertaking sensitive research, Gov.UK (2019) guidelines recommend learning about the subject matter to prevent them feeling overwhelmed, and this will help the participants to feel comfortable and talk openly. I contacted professional support services to help me with my preparatory work for this research.

**Reflective box**

I had delayed contacting my local SARC for weeks because I felt anxious without understanding why. A SARC is a specialist medical and forensic service for anyone who has experienced SAV whether they have reported it to the police or not. When I eventually plucked up the courage to call, the receptionist put me at ease. I explained my role as a PhD student and asked if I could arrange a visit as part of my research preparatory work. It was important to be familiar with the process that survivors go through whilst seeking support. She seemed interested in my work and we arranged a visit. It was a Monday morning and I was surprised at how nervous I felt. Whilst travelling I had different thoughts swirling around in my head. It felt surreal. This was different to reading books, journals and electronically searching SAV. I was about to meet SAV in person and be faced with its reality. It would be a testament to how I would manage emotional challenges. Although I was well-versed on the roles of an ISVA and SARC, I did not know what to expect when I arrived. There would be no closing of a book, turning off my laptop, and no more distancing myself from SAV if it got too uncomfortable. This felt different, this felt real. I was not a victim; yet, I felt as though I was going through the motions of a survivor seeking support. I was asking myself many questions - how did it feel for survivors whilst seeking support? How did they feel about making that initial phone call? The visit? Telling their story to a stranger? And probably not for the first time. These thoughts, feelings, and anxieties were heightened when I realised that I had got lost. I asked a local shopkeeper for directions to the SARC and I immediately felt exposed. I

wanted to explain that I was not a victim and that I was there for research purposes. I was directed to the SARC which was a two-minute walk, yet it seemed like miles. I remember looking around to see if anybody knew me, and then I hesitantly rang the doorbell. The ISVA welcomed me and it was eerily quiet. No-one else was there. She discussed the process that people went through whilst seeking support. I had a tour of the SARC and I viewed the examination room. It was designed to be welcoming, homely, adorned with soft furnishings, yet, beyond the décor it felt, *cold*. It still felt clinical, but realistically how inviting can a medical room be when its purpose is to examine sexually violated people. I observed the medical equipment for collecting forensic evidence such as semen, urine, and blood samples. A colposcope to photograph physical injuries to the vaginal area. It unnerved me. Attached to the medical room was a shower room which did not have a personal feel about it. Sanitary products and fresh underwear were available for survivors. I observed the storage space for clothes that may be stored to preserve forensic evidence in case the victim decided to report at a later time. As I continued my tour the phone rang. A young lady had been raped at the weekend, and as the ISVA talked her through the process, I realised how lucky I was not to be that person at the other end of the line.

The tour was insightful and I was filled with mixed emotions. I realised that the literature alone did not portray the reality of rape. It merely gave me a glimpse into the implications of SAV. It did not offer a true reflection of the stark reality, the brutality, the damage, the aftermath, its complexity caused by a crime which can take the life out of a person. The reality of rape is 'thinking' and 'feeling' the pain of those who have fallen prey to the hands of the abusers.

I had discussions with an ISVA and I familiarised myself with her role of supporting survivors of SAV. I learnt about the emotional impact it had on the survivor, and herself whilst providing emotional support. She informed me about the importance of regular supervision, self-care and contact with counsellors if needed. The gatekeeper for this research enlightened me about the support needs of victims, and also protecting his own psychological needs. I engaged with counsellors and I learnt about various therapeutic interventions. If a specific approach did not meet the needs of their clients, they could refer them to someone who specialised in the area required. It was beneficial to work alongside colleagues whose expertise was in mental health who supported autistic and non-autistic individuals. I attended fortnightly meetings to discuss our well-being which was worthwhile as we supported each other through our challenges and achievements.

Within qualitative research, protecting human participants is a sacred obligation but more so for a researcher conducting IPA (Alase, 2017).

As a qualitative research study, it is imperative and ethically important that an IPA study is cognizant of the right and privacy of the individuals participating in the project. It is anticipated that participation in any IPA study will be strictly voluntarily based and the risks to the participants should be very minimal. It is, however, important that no harm should come to the participants in an IPA study. IPA research study should provide adequate measures of protection for the rights and dignities of its participants, because participants in an IPA study should be better off knowing they were able to tell the stories of their “lived experiences”; not worse off from it. (Alase, 2016, p. 92)

The following safeguards were implemented to ensure that safe and responsible ethical practice took place throughout this research. The participants’ voluntary and informed consent is essential in any research and provides them with information relevant to the study (Ritchie and Lewis, 2003). It was imperative that the participants understood their role in this research and the implications involved. I explained what it incorporated and answered their concerns (Jones, 2012). They were informed verbally at the outset of the study that their participation was voluntary, and free to withdraw up until July 30<sup>th</sup> 2017 without giving reasons and no consequences would be incurred.

Ensuring confidentiality and the anonymity of participants whilst reporting research is considered good practice by RECs. It is expected in legal frameworks such as the UK’s Data Protection Act (1998) and more recently General Data Protection Regulation (GDPR). I discussed confidentiality at the start of the interview and I informed the participants of the safe storage and handling of the data collected. With their permission all interviews were audio-recorded. Data were stored safely until

completion of the research with the intention to destroy them at the end of the study. This allowed Good Practice and within the guidelines of the UK's data protection regulations. Each transcription was coded and so data were anonymised to ensure that participants could not be identified. Any quotes or data used within publications were anonymised (Ritchie and Lewis, 2003).

Consideration was given to disclosure or nondisclosure of harmful or illegal activity that could present ethical dilemmas. If criminal activity is disclosed there is not usually a legal obligation for the researcher to disclose the information unless there are legal investigations proceeding (Corti, Day, and Backhouse, 2000). They will only be guilty of perverting the course of justice if the enquiries are intentionally avoided (Corti, Day and Backhouse, 2000). The exclusion criteria for this research specified that there would be no involvement in police enquiries or legal proceedings at the time of data collection. An important ethical dilemma may arise if there is an indication that the participant is at risk of harm during the interview, and whether confidentiality should be broken as it raises issues regarding the participant's consent (Ritchie and Lewis, 2003). It would be unethical to report observations or anything disclosed if the interview is confidential unless the participant consents. Harm could be intensified if information is passed on that is non-consensual due to the possibility of experiencing a profound loss of control. It is recommended that after the interview, the researcher encourages the participant to report it themselves or to support them in pursuing help if desired (Ritchie and Lewis, 2003).

Another safety consideration was that of subterfuge or undisclosed research activity. Deceptive research can be made compatible with informed consent and Miller, Wendler and Swartzmann (2005) suggest using authorised deception. Participants

can be informed prior to deciding whether to volunteer for a study that the experimental procedures may be deceptive, allowing them to decide whether they wish to participate. My research design did not use deception and it was clear, transparent and inclusive. It was crucial to consider that participating in sensitive research may be harmful for participants exposing painful experiences that are seldomly shared, and aversion action is required (Ritchie and Lewis, 2003). It is essential for the interviewer to monitor how the participant is affected due to ethical reasons and because IPA is frequently associated with existential issues (Pietkiewicz and Smith, 2012; Smith, Flowers and Larkin, 2009), and I adhered to those guidelines. The ending of the interview was handled sensitively regarding how the participants might react to revisiting painful memories that could trigger PTSD. I gave each participant a self-referral package and I discussed its content reinforcing the available support networks. I informed them that I would help to direct them to appropriate support services if required. Five participants did not want support after the debrief. One participant who was emotional throughout the interview, but wanted to continue because it was the first time she was able to tell her story, met with Victim Support at the end of her debrief. They offered her additional support but she felt they had met her support requirements. She assured them that she would contact them if she required further support. I too had strategies in place to meet my psychological needs and I had a debrief similar to the participants. Victim Support were available at the end of each interview if needed, and I checked in with a trusted colleague. Leaving the participant and researcher relationship required a considerable amount of emotion work because the boundaries could become blurred if I had not effectively managed them (Dickson-Swift et al., 2006).

The REC raised an important point regarding the safety measures for this research and they advised utilising the support of a trusted colleague, and they were rigorous about the suitability of his position. He was a mental health specialist in receipt of professional insurance to practise as a therapist. He was competent in identifying emotional and mental harm. If he recognised that the harm was too great for me, we would discuss it and inform my supervisors who would suspend the research if needed. We discussed the duties of his role in accordance to the requirements of the REC. I would log-in and log-out before and after each interview which reinforced safety measures allowing for an immediate debrief. The REC recommended that he accessed and stored information about the time and location of the interviews. The information was recorded in paper form and handed to him in person on the day of the interview. He kept the information securely in a locked filing cabinet in an office at the university where we worked. He was the only person with access to the key. The information was shredded immediately after I had logged-out of the interview.

Ethical guidelines were followed through to the dissemination of this research. The object of dissemination is to maximise the impact of the study by getting the messages across to those who could benefit from it (Tarling, 2006). I produced a brief synopsis of the research to inform participants of the outcome and a full report was obtainable upon request. The results were accurately presented and I demonstrated transparency to ensure that they were reliable and credible.

### **3.24 Interview schedule and research questions**

Pietkiewicz and Smith (2012) recommend preparing an interview schedule in advance of conducting semi-structured interviews as a guide in facilitating a naturally flowing

conversation. I considered the design of the schedule and research questions, particularly as they frame the study, data collection and analysis (see Appendix IV for the interview schedule and questions). The word 'interview' was not used with the participants as it could have negative connotations and it was referred to as a 'discussion' or 'meeting'. The use of language was important because it is a powerful mode of communication which can evoke positive or negative responses. 'Interview' could be linked to the disclosure process whereby the participants may have been interviewed, and terminology could resurface painful memories. I was mindful of my language and how I phrased the research questions whilst designing them and the schedule.

To produce valid and reliable data, there needs to be consistency of the research questions and methods to lend itself to a good research design (Ritchie and Lewis, 2003). The interview schedule and questions were developed in line with qualitative research and the use of semi-structured interviews regarding IPA. I began developing the schedule and questions by revisiting the three research questions that were intended to answer the main research question which are restated below:

1. How do autistic individuals make sense of their lived experiences of SAV?
2. How does being autistic increase sexual vulnerability?
3. What are the implications for policy, practice and support?

I outlined the literature relevant to answering the research questions, and I formulated them in line with the research pertinent to autism and SAV. The existing literature formed the basis of the research questions to make an original contribution to research. Developing an interview schedule influences the comfort of the interaction

between the researcher and the participant enabling them to give a detailed account of their experiences (Smith, Flowers and Larkin, 2009). This would allow the participant to take direction of their interview (Huws and Jones, 2015).

Whilst designing the research schedule, I included the development of rapport building between myself and the participants. I considered the individual needs of the research sample, particularly because of their vulnerability. The flexibility of qualitative research was pertinent to the research schedule as it enabled two-way dialogue. The schedule and questions were grounded, and positioned epistemologically in line with IPA (Smith, Flowers and Larkin, 2009), including key areas of interest relevant to the study (Pietkiewicz and Smith, 2012).

The questions were fundamental because of their association with all aspects of the research design (DeJonckheere and Vaughn, 2019). Initially, they were too broad and subsequently, I categorised them into specific sections. I redefined the questions and differentiated them into main headings. I utilised the words 'what' and 'how' to explore the participants' experiences of SAV and how they were interpreted. 'When' and 'why' were used to find out the meanings of their particular events. In line with the theoretical underpinnings of IPA and to gain the insider perspective, the questions were designed to be open allowing the participant to tell their story at their pace, and in their own words (Huws and Jones, 2015). It permitted back and forth movement of topics relevant to the discussion. This was beneficial due to the individual characters of each participant and their experiences. It enabled a divergence in each interview allowing me to gain a deeper understanding of their phenomenon. It added to the nuanced and rich primary data that was collected.

Some participants may struggle with open-ended questions if they have difficulties in expressing themselves but they can be modified to be focused, direct, concrete, and not too abstract (Ritchie and Lewis, 2003). This type of communication can be well suited for autistic individuals who are literal and/or may have difficulties understanding spoken language. The questions were clear, concise and leading language was avoided (DeJonckheere and Vaughn, 2019), and I used familiar jargon free language. Although I designed the questions to be non-abstract, prompts were incorporated into the interview schedule to help the participant understand any questions that were unclear (Pietkiewicz and Smith, 2012).

Smith and Osborn (2007a) suggest that participants are given maximum opportunity to tell their story as they are the experiential experts. Most IPA interviews have a duration of one hour or longer (Pietkiewicz and Smith, 2012). I considered the cognitive processing time of the participants which may have taken up additional time. The participant information sheet stated that it would take approximately two to three hours, but either less or more time may be required. This allocation enabled each participant to detail their experiences and it allowed time for breaks if they became overwhelmed. Sensitive facilitation is required whilst supporting people to describe their feelings that are distressing or may otherwise have been unexpressed (Ritchie and Lewis, 2003).

The final section of the research schedule incorporated the ending of the interview. I was mindful that the interview could be a cathartic experience for the participants, and the possibility of them benefiting from telling their story to someone who was interested in what they had to say. Ending the researcher and participant relationship needed to be managed sensitively and sufficient time was allocated for de-briefing. It included a

discussion regarding how the participant had been affected by the interview. I gave them an information package and discussed its contents, and if further support was required I was available to help them with the process.

Upon completion of the interview schedule, I reflected upon its design. Adjustments were made to ensure that it was effectively designed to answer the research questions. I then checked back to the three research questions and I was confident that it was fit for purpose.

### **3.25 Data collection: Semi-structured interviews**

I chose semi-structured interviews as a method of data collection because they are the preferred way of collecting data for an IPA study (Biggerstaff and Thompson, 2008; Eatough and Smith, 2008; Humphrey and Lewis, 2008; Reid, Flowers and Larkin, 2005; Smith and Osborn, 2007a). IPA is best suited to a data collection method that “invite participants to offer a rich, detailed, first-person account of their experiences” and “facilitate the elicitation of stories, thoughts and feelings about the target phenomenon” (Smith, Flowers and Larkin, 2009, p. 56). To acquire the insider perspective from autistic individuals, semi-structured interviews are a conducive way of giving them a much-needed voice (Humphrey and Lewis, 2008). They may be disadvantageous whilst interviewing individuals who have communication difficulties (DeJonckheere and Vaughn, 2019). The inclusion criteria for this research stated that the participant was required to communicate spoken language, but I was mindful that they could misinterpret the questions, be literal, and use echolalia. Semi-structured interviews involve discussion between the researcher and participant and allow for

follow-up questions, probes, and comments because of the flexibility of the interview protocol (DeJonckheere and Vaughn, 2019).

There are numerous ways in which semi-structured interviews can be undertaken (DeJonckheere and Vaughn, 2019) and I conducted face-to-face interviews. In line with emotion work theory, the intention was to capture emotionality which might not be the case with other data collection methods including questionnaires, surveys, online forums and telephone conversation. Pietkiewicz and Smith (2012) emphasise the awareness of verbal, non-verbal, and non-behavioural communication. Semi-structured interviews permit the interviewer to observe the participant's body language. Emotional cues can be interpreted via tone of voice, laughter and fundamentally, silence. Silence can be a powerful mode of communication although some individuals may feel uncomfortable with it. "Instead of always trying to avoid silence, sometimes we ought to embrace it" (Bengtsson and Fynbo, 2018, p. 37). Pietkiewicz and Smith (2012) highlight the importance of the researcher feeling comfortable with silence because it allows reflection time for them and the participant. Similarly, Ritchie and Lewis (2003) encourage the interviewer not to fill the pauses as contemplative silences can be productive. It adds meaning during the interview and may produce valuable data (Bengtsson and Fynbo, 2018). The researcher can obtain more depth and an enriched understanding within the interview process as important clues are found in body language and speech patterns (Ritchie and Lewis, 2003).

Semi-structured interviews were well suited to this research because it allowed a deep exploration of the participants' personal issues (DeJonckheere and Vaughn, 2019). The flexibility allows the interviewer to develop novel perspectives or topics that may arise, and they can obtain more detail with further questioning (Pietkiewicz and Smith,

2012). One-to-one interviews can be managed with ease and a good rapport can be built up allowing the participants to have space to think, speak and be heard (Cridland et al., 2014; Smith, Flowers and Larkin, 2009).

### **3.26 Rapport building**

Whilst undertaking sensitive research, an important preliminary is establishing rapport, and it involves the researcher managing their emotions and those of the participants (Dickson-Swift et al., 2009). Building up a good rapport with the participants was important to form a relationship of mutual trust and acceptance, particularly as the interview involved intimate questioning. This was achieved by ensuring that the participant was comfortable with the location of their interview, and that it was safe for all involved and free from interruptions (Smith, Flowers and Larkin, 2009).

I found that a gentle starting point for rapport building was to find out the area of interest of the participant, and this was a good ice-breaker putting us both at ease. A good rapport was quickly established and I swiftly moved to the next stage of the interview process. The participants consented to the interviews being audio-recorded (Robson, 2011). I explained that the data would be kept securely and that only I would have access to it, and it would be destroyed upon completion of the study in compliance with the UK's data protection regulations. Inevitably, I asked them their story of SAV which I did in the early stages of the interview, and I sensed their relief as each participant was eager to tell their story.

### **3.27 Data analysis**

I utilised an IPA framework for the data analysis, incorporating emotion work and emotional labour to enhance the in-depth interpretations of the participants' experiences. I accrued a copious supply of data from the interviews. Upon completion of each interview, I transcribed the audio-recordings verbatim (see Appendix V for an example transcription). I printed each transcription so it was in physical form, and I re-read it ensuring that I had a clear understanding of the lived experience of the participant. I made annotations on the transcriptions and I used post-it notes to highlight interesting descriptions. I immersed myself into my reflective journal and field notes that I had made throughout the research. I looked across the accumulated data for similarities and differences aiding transparency and credibility to the findings. I listened to the audio recordings of each participant's interview several times to familiarise myself with their words (Holloway, 1997). It enabled me to get a good feel of their state of mind and how their experiences had affected them (Alase, 2017). I started the analytical process of line-by-line data coding to identify common themes and the repetition of words or phrases to condense the words or sentences within each transcript (Alase, 2017). Line-by-line coding enabled me to stay close to the data and develop a credible interpretation of the experiences of the participants. The left-hand margin was used to annotate interesting words or idioms, initial thoughts and interrogative comments (Smith, Flowers and Larkin, 2009). I re-read the transcript and used the right-hand margin to note any recurrent thoughts, repetitions and emerging themes evolving from the transcript and preliminary analysis. I used an analytical process proposed by Smith, Flowers and Larkin (2009) to aid "exploratory commenting" (p. 83), and the intention was that it would not be exhaustive or prescriptive, but could be utilised as an optional tool in the data interpretation. Descriptive comments focused on describing the content of what the participant had

said, the subject of the talk within the transcript (normal text). Linguistic comments focused upon exploring the specific use of language by the participant (italic). Conceptual comments focused on engaging at a more interrogative and conceptual level (underlined) (Smith, Flowers and Larkin, 2009, p. 84). (See Appendix VI for an example of how this was demonstrated).

Essentially, researchers should proclaim their preconceived ideas and think about how their subjectivity is integral to the analysis (Moran, 2000). I attempted to limit any preconceptions with the potential of tainting the research process (Tufford and Newman, 2012) but inevitably there will have been some subjective interpretation. IPA is concerned with reflexivity for the researcher to own their own bias. I reflected upon my personal bias throughout the research and how it influenced the analysis. Upon completion of the coding, I extracted the themes and listed them. I wrote the codes on labels and placed them on the floor. The graphics were helpful as it was easier to identify any connections between the themes as I could move them about and group them together. As recommended by Pietkiewicz and Smith (2012), I began to work more with my notes as opposed to the transcript to transform them into emergent themes, and I explored connections between them. I collated themes for each transcript and I disregarded those that lacked evidence to support the emergent themes. I then began to connect emerging themes, and I organised them in accordance with conceptual similarities, thus giving each cluster a label that was descriptive (Pietkiewicz and Smith, 2012). In alignment with IPA's idiographic philosophy, I examined each case meticulously before exploring cross-cases (Miller and Casey, 2016). Once I had identified the clusters, I moved on to cross-case analysis and I looked for patterns of convergence and divergence that "shared higher

order qualities across cases” (Finlay, 2011, p. 142). Similar themes emerged from the data analysis and I put a name to the over-arching superordinate themes.

The table below is an example of the themes emerging from a semi-structured interview and this analytical process was followed for each participant.

**Elsie (participant 6): Table of themes from IPA semi-structured interview**

<b>Master Theme Titles</b>	<b>Emerging subordinate themes</b>	<b>Transcript Key Words</b>	<b>Page and Line Numbers</b>
<b>Establishing my sense of self/identity</b>	Who am I?	“...is that because, erm of the autism? Or is it because of my experiences?”	p. 21. 515-516
	Pretending to be normal	“I present as someone that does not appear to have any autistic traits whatsoever, but I’ve got so used to sort of hiding that”	p. 21/22. 522-524
	People-pleasing and co-dependency	“...I’m a people-pleaser, well and truly...”	p. 12. 303-304
<b>A cycle of abuse</b>	Normalisation and grooming: Power, control and manipulation	“...he had started grooming, started preparing from when I was fifteen and taking little steps like wearing me down, making me feel like it was normal you know”	p. 12. 288-290
	Who’s controlling who?	“...they I wanna say it was they but cus I wanna feel like my mum just didn’t let him do everything that she was had some level of control, but yeah” [crying]	p. 4. 82-84
<b>Re-living it all over again</b>	Self-blame as a barrier to disclosure	“I kept doubting myself more and more and more	p. 33. 804-806

	Re-traumatisation	that actually I'm wrong about the situation, and that there isn't anything here that the police can do. There's isn't a crime to be reported" "...I could never get out of it. I was constantly reliving it, re-feeling it"	p. 32. 792
<b>Delivering appropriate sex education</b>	Sex education versus social media	[pornography] "...it's the first time I'm seeing something like that. I'm actually intrigued. I want to see it cus I want to know erm like how do men and women have sex"	p. 6. 139-141
	Role of social media in sex education	"Like to me I feel hopefully and I think it's better that sex education should be more of actual sex education, because, otherwise, people are just going to constantly keep learning about it from online, and porn, and tv programmes and that is not what sex is about"	p. 33. 814-817
	Diversity acceptance	[diversity] "...but I want that normalised and reduced"	p. 35. 859

### 3.28 Trustworthiness: Credibility and reliability

IPA attracts some criticism regarding its trustworthiness. “Critics of IPA suggest that it is unscientific, lacking a complex subjectivity and displaying a promiscuous epistemology” (Dennison, 2019, p. 1). Trustworthiness for this research was ensured at the outset through a holistic and transparent approach. Honesty and integrity were vital to the entire research process. This was achieved by engaging in reflexivity and acknowledging my role as the researcher. I considered my own belief systems and judgements that may have unwittingly influenced the research. My reflective journal was used effectively enabling me to reflect on my decision-making. I kept a log of my thoughts, feelings and emotions as I made sense of the data which is demonstrated in my positionality statement, reflection boxes and the analysis. Journaling enhanced the credibility of the research providing a means of auditing (Glaze, 2002). Detailed and accurate record keeping was conducive to determining its credibility. Yin (2003) suggests that documenting the steps taken in the research process adds to its reliability.

To ensure credibility of this study, I considered my personal biases whilst attempting to transcend them to avoid biasing the research process, analysis and findings. I was not emotionally detached from the research and I was attentive towards my emotional state and that of each participant. The openness of my approach enabled the reader a truthful insight into my own perspectives and those of the participants. I utilised a range of strategies to validate the credibility and reliability of the research. IPA is not looking for ‘absolute truths’ per se and I have recognised that my participants may give different interpretations of their experiences at dissimilar times. The interpretative nature of phenomenology indicates that the intricacies of the method used by separate researchers will not produce the same outcome (Cope, 2004).

Patnaik (2013) advocates for the researcher's voice to be heard to lend itself to the credibility of the research, and to better embed itself in the epistemological context. As recommended by Creswell (2009), I spent time engaging myself in the setting of the participants to gain an in-depth understanding of the phenomenon under discussion, adding credibility and reliability to the findings. I had discussions with male and female autistic and non-autistic survivors of SAV. I was interested in how it had affected themselves and their relationships with others. I engaged with various support services and I had in-depth conversations with professionals who worked with survivors. I immersed myself in the literature relevant to SAV and I read multiple blog articles of survivors who identified as sexually diverse. This contributed towards a comprehensive understanding of the experiences of SAV aiding credibility and reliability to the findings.

### **3.29 Summary**

This chapter emphasised the implications associated with undertaking complex research with vulnerable individuals. The inclusion of disabled participants in sensitive research is feasible if the ethics are robust and strictly adhered to. The safety needs of the researcher and the participant are of equal importance and with appropriate safety measures in place, complex research can effectively be undertaken. Excluding disabled participants who are eager to participate could potentially undervalue the research process and findings. This research highlighted that they have much to offer by voicing their experiences. Frequently, researchers are discouraged from addressing sensitive topics because of the RECs barriers (Butler, Vincent and Bluebond-Langner, 2020). I hope that I have demonstrated that it is possible to

conduct complex research in the face of adversity. It was through my passion for the subject, and the importance of giving autistic individuals a voice, that I had the determination to gain ethical approval. I was able to convince the REC that not only was this research worthwhile but very much needed.

## CHAPTER 4

### SUPERORDINATE THEMES AND RELATED SUBORDINATE THEMES

#### 4.1 Introduction

This chapter offers the reader a narrative and interpretation of each participant's lived experience of SAV. It gives an insight into the implications of SAV from autistic survivors which is missing in the current literature. The theoretical aspect of emotion work helped in the interpretation and sense making of the data, and the understanding of 'thinking' and 'feeling' rape which is not captured in research publications. A brief synopsis of each participant provides background information. An interpretative phenomenological approach was used to analyse the research findings and six superordinate themes emerged: 1. The bleeding edge of autistic pain. 2. My dysfunctional family came at a cost. 3. Autistic chameleon in a crowd. 4. Rape culture: The reality beyond the myth. 5. Specialist support services: Where are they? 6. The importance of sex education for autistic people: The missing pieces? I briefly summarise them, and then I detail the results and discuss the relevant literature in the field to support the findings. I incorporate emotion work to add nuance and depth to the analysis.

It is worth briefly restating the justification for incorporating my experiences and emotions into this research. I describe the theoretical framework of emotion work that serves as a roadmap in the context of laying the foundation for the development of the arguments put forward throughout the research. Emotion is seldom acknowledged in research methods teaching or textbooks despite it being an inherent part of knowledge production (Ferrie and Greenwood, 2023). Undertaking sensitive research which is

emotion-laden involves emotion work. This fits well with the reflexive nature of IPA requiring the researcher to reflect upon their own emotions and experiences providing a valuable data set in itself. Ferrie and Greenwood (2023) recommend incorporating difficult emotions into the research process and sharing how we respond to difficult situations to gain insight into the messiness and complexity of it. In line with the philosophical underpinnings of IPA, I refer to my reflective journal. As previously discussed, I incorporate my emotionality and experiences which are demonstrated in reflective boxes. Each participant's experience is equally important but some of the excerpts elicited strong emotional feelings and I have included them throughout this chapter. The notion is not to detract from the participants' lived experiences, but to enhance the richness of the findings, providing a holistic and transparent approach.

To answer the research questions, the lived experiences of each participant are detailed and their emotions are interpreted as they offer a valuable source of knowledge. Emotions provide accurate and in-depth understanding of the phenomenon. They are incorporated into this study to frame the theoretical underpinnings that guided the research, its structure and approach, and the interpretation of the findings. To remind the reader of what I hope to achieve in bridging the gap in research, I restate the research questions below:

1. How do autistic individuals make sense of their lived experiences of SAV?
2. How does being autistic increase sexual vulnerability?
3. What are the implications for policy, practice and support?

The following tables demonstrate participant demographics and interview conventions:

### PARTICIPANT DEMOGRAPHICS

**Table to illustrate participant demographics**

<b>Participant</b>	<b>Gender</b>	<b>Age</b>	<b>Ethnicity</b>	<b>Sexuality</b>
Daisy	Female	22	White British	Heterosexual
Elijah	Male	25	White British	Gay
Thom	Male	46	White British	Non-gender differentiation
Gwen	Female	22	White British	Bisexual
Amy	Female	21	White British	Bisexual
Elsie	Female	29	White British	Bisexual

### INTERVIEW CONVENTIONS

**Table to illustrate interview conventions**

<b>NAME</b>	<b>DATE</b>	<b>LENGTH OF INTERVIEW</b>	<b>WORD COUNT</b>
DAISY	19.12.2017	3:45:20	21982
ELIJAH	09.06.2018	0:55:24	6256
THOM	30.07.2018	1:47:48	11100
GWEN	23.11.2018	1:48:46	17258
AMY	02.04.2019	1:06:52	5172
ELSIE	05.07.2019	1:36:12	13846

Transcript Conventions:

... = Short pause

..... = Long pause

*Italics* = Emphasis of the word/s

The following is a brief synopsis of background information about the participants' lived experiences, and presented in the order that the interviews took place. Each participant chose a pseudonym which anonymised their name.

### **1 - Daisy**

Daisy is a twenty-two-year old white British female and she received an autism diagnosis aged twenty. She is also diagnosed with non-epileptic disorder due to the pressure of SAV and it was her body's way of coping with PTSD. She is heterosexual with a sexual preference of BDSM. She attended a mainstream school and progressed to university. Daisy experienced SAV including molestation at the age of eight by her older cousin; rape by her boyfriend aged sixteen; groomed by a friend which led to gang rape; and groomed and anally raped by a teacher. She also had a difficult home life. She became depressed and engaged in self-destructive behaviour including self-harm, promiscuity, substance misuse and attempted suicide. She did not benefit from therapeutic services and believes this was due to not having an autism diagnosis at the time and subsequently, she did not receive appropriate support. Writing poetry was the start of her recovery process. She engaged with friendship groups, drama, art-work and journaled her experiences to aid her recovery. Her innate ability to spiritually connect with horses was the catalyst to wanting to live.

Daisy took part in this research to raise awareness of SAV to help and protect other autistic people. She reflected upon the murder of her friend by someone they mutually knew who then raped her. Daisy commented "I could've bin the girl laying dead in the ditch". Referencing SAV she said "it has to stop".

### **2 - Elijah**

Elijah is a twenty-five-year old white British male and he received an autism diagnosis aged nineteen, and he is also dyslexic. He is gay and engages in BDSM and oral sex, but rarely participates in anal sex. Elijah progressed from special educational needs and pupil referral units to university and achieved a Bachelor of Science degree. He was abandoned by his mother and was raised by his father, but predominantly his grandmother. At the age of eighteen, Elijah was anally raped by a man that he had met online, and anally raped by a man he dated aged nineteen. Due to being raped he became addicted to pornography affecting all areas of his life. Elijah's therapeutic support was effective and it was tailored exclusively to meet his needs as an autistic person. He made a recovery over an eighteen-month period and made a seamless transition from disclosure to accessing support. He commented that there is no available information identifying autism specific SAV support for either gender.

Elijah was eager to contribute to this research to raise awareness of the taboo of male-on-male rape, and to encourage other victims to come forward and access support.

### **3 - Thom**

Thom is a forty-six-year old white British male and has diagnoses of mental health including anxiety, depression, bi-polar, schizophrenia, oppositional defiant disorder and intermittent explosive disorder. He received an autism diagnosis aged thirty-nine and believed he had a misdiagnosis of schizophrenia. Thom identifies as “sexual” and has sex with men and women but does not consider himself to be bisexual because he does not gender differentiate. He is uninterested in a person’s body but is attracted to their mind which he categorises as genderless. He engages in sex that he says most people would refer to as “kinky”, but Thom perceives that BDSM is normal and plays the dominant role. He was educated at an all-boys grammar school and attended an elite university, and he is extremely aware of his high level of intelligence.

Thom had a difficult childhood. He detested his father but he had a good relationship with his mum supporting her throughout her battle of terminal cancer. He endured historic sexual, physical, financial and psychological abuse. He was sexually abused by two of his teachers aged eight; sexually abused from the age of thirteen by his teachers; sexually abused by much older affluent women from the age of thirteen to nineteen; physically abused in his early twenties; and financially abused. He engaged in self-destructive behaviour as a coping mechanism.

He eloquently summed up his reasoning for participating in this research “...as autistic people we are very vulnerable. We do tend to be subject to abuse. We quite often don’t recognise it as abuse, and anything that gets attention to *that* is a good thing. So, I think the project is not just worthwhile but necessary, and being able to contribute to that is a privilege. There was absolutely no question in my mind, that that’s what I should do. How do you go about changing the world? You start with the information, and you start by disseminating the information to people and saying well this is why the world is wrong, and this is what needs changing, and here’s how we change it. But without saying what needs to change and what’s the incentive, this project is about what needs to change. Why are we vulnerable? Erm and why given that it’s known why we’re vulnerable, why are we not taken seriously?”

### **4 - Gwen**

Gwen is a twenty-two-year old white British female and she received an autism diagnosis within a year of her interview. She also has diagnoses of anxiety, depression, episodes of psychosis, and an eating disorder. She identifies as bisexual and engages in BDSM. She attended a mainstream school and progressed to university. She withdrew from her studies because of the long-term effects of SAV. Her home life was difficult and she witnessed physical and psychological abuse from when she was “tiny”. Gwen portrays a graphically detailed description

of the violence she experienced. She was sexually abused by a family friend aged about six; coerced into posing for sexually explicit photographs by her teacher aged ten; and sexually violated by her boyfriend. She then got into an abusive relationship with someone who knew about her previous abuse. He too sexually violated her and prostituted her to his friends. She was psychologically affected by several miscarriages. She engaged in self-destructive behaviour as a coping mechanism including self-harm, substance misuse and attempting suicide. Throughout her narrative she laughed and joked about her trauma known as gallows humour. Gwen's participation in this research was to have her voice heard "I've never really spoken about it before. Every time I have its kinda made things worse. So, this seems like an opportunity to do something, and it will make things better rather than worse. It will help, in some way, hopefully".

### **5 - Amy**

Amy is twenty-one years old and is a white British female. She has diagnoses of borderline personality disorder (BPD), depression, anxiety, (OCD), and dyspraxia. She received a diagnosis of Asperger's syndrome aged sixteen whilst at Child and Adolescent Mental Health Services (CAMHS). Amy is bisexual and has a sexual preference of BDSM. She attended mainstream school and progressed to university. Amy did not recover from brutal SAV resulting in pregnancy which ended in miscarriage. Her overwhelming feelings of loss and grief are paramount in her narrative whereby she laid bare the depth of her raw emotions. Her story evokes painful memories which she blocked out. To cope with her pain and to relieve her numbness, she engaged in self-harm. Amy sought love to "fill the void" of her loss and she got into a sexually abusive relationship. The prevalence throughout Amy's story is that it is teeming with emotion. There is a dichotomy between the presentation of her emotions and the language used to describe them possibly relating to alexithymia.

Amy wanted to participate in this research to raise awareness to help other people survive SAV. "I wanted to open up and get all the emotions out, and just being able to feel some kind of relief because I've just kept it in for so long that I just didn't know who to trust, and it's just built up over time. Erm but the main important reason that I wanted to speak out was to help other people because the thought that it happened to me killed me, but the thought of it happening to other people kills me even more. I want to make a difference to helping other people, survive".

### **6 - Elsie**

Elsie is aged twenty-nine and is a white British female. Her autistic boyfriend recognised that she displayed symptoms of autism. She followed the diagnostic route and she was diagnosed sixteen weeks prior to her interview. She also has BPD, anxiety and depression. Elsie is bisexual and regarding BDSM she commented "female control orientated, that's where I kind've go". Elsie attended mainstream school and progressed to university. Her home life was unstable. Her dad left home and she was raised by her mum and grandparents. Her mum re-married and Elsie was groomed by her step-dad when she was aged fifteen and he

raped her at seventeen. She was also coerced into acquiescence by her step-dad's cousin and he inappropriately touched her. Elsie was financially abused by her step-dad and mum. She eventually disclosed to her mum that her step-dad had raped her. Her mum revealed that he had raped her too. Elsie's step-dad had historically sexually abused a girl and her mum "*knew*" about it. Elsie had a "breakdown" due to not protecting her younger sister from her step-dad's sexual advances. She engaged in self-destructive behaviour as a coping mechanism and attempted suicide. She was retraumatised by the CJS and support services.

Elsie was keen to participate in this research to raise awareness for autistic survivors of SAV. She hoped that her participation would make a positive contribution towards the research to prevent it from happening to others.

The instant connection I made with each of my participants was poignant. I deem that it fundamentally enabled them to feel comfortable whilst effectively articulating their lived experiences of SAV within the interview process.

#### **Reflective box**

I instantly connected with each participant upon our initial meeting. I believe this was because we were all interested in the subject matter. Although I have not experienced SAV, I made it known that we shared traumatic experiences and this seemed to compound our connection on an emotional level. I introduced the concept of emotionality at the outset of the interview process making it clear to the participants that the subject was highly emotive. I explained that their emotions could be expressed in a way that was meaningful to them, particularly as it can be difficult for some autistic people to effectively communicate and express their emotions. I provided a box of tissues for both of us, and I made a point of saying they were there, if needed. This small gesture was an acknowledgement of the pain that they could experience. Seemingly, it gave them the approval to cry without the fear of embarrassment. Based on the emotionality that is involved with SAV, it was fundamental to include my own experiences and emotions into the research. This approach enhanced all aspects of the research process starting from meeting with each participant through to the data collection, analysis and findings. Emotions are an integral part of being human, and I felt that it would do the research a disservice if they were not included. I assured the participants that they would not be judged and that anything they told me, would not shock me. I informed them of my background and how I had worked with autistic survivors of SAV, and that I had been privy to horrific cases. This seemed pivotal in putting them at ease as it seemed to give them permission to fully tell me their story without causing me distress.

## **4.2 Summary of superordinate and subordinate themes**

I followed the analytics process discussed in the previous chapter, and close interpretation of the data allowed the following superordinate and subordinate themes to emerge. I offer a brief summary of each theme and then I detail them with a discussion supported by relevant literature in the field.

#### **4.2.1 The bleeding edge of autistic pain**

This superordinate theme demonstrated the distress of each participant because of their experiences of SAV that severely impacted upon their physical and psychological well-being. It has three subordinate themes:

1. *I am so utterly vulnerable* - signified the vulnerability experienced by each participant because of traumatic events.
2. *Coping mechanisms* - demonstrated the self-destructive behaviour of each participant to relieve their pain.
3. *The dissociated-self* - exemplified how the participants depersonalised SAV and dissociated to disconnect from the pain that they experienced.

Refer to Table 1 in section 4.3.

#### **4.2.2 My dysfunctional family came at a cost**

This superordinate theme highlighted the damage of living within a dysfunctional family environment, and the influence it had on the participant's decision to disclose SAV. It has four subordinate themes:

1. *My dysfunctional family and me* - revealed the damage experienced by five participants due to being raised within an adverse family environment.
2. *All I need is love* - afforded insightful reflections by the participants as they tried to fill a void in their lives by engaging in risky behaviour.
3. *I can't tell you - it's my secret* - demonstrated the empathy of each participant by not disclosing their abuse to protect their family from further pain.
4. *The ripple effects* - identified that when the families discovered that their child had endured SAV, they too experienced adverse reactions to the disclosures.

Refer to Table 2 in section 4.4.

#### **4.2.3 Autistic chameleon in a crowd**

This superordinate theme focused on how the participants camouflaged their true authenticity enabling them to be accepted into society that is all too often ableist. It has four subordinate themes:

1. *Identity issues: Who am I?* - encompassed the confusion of each participant because of receiving a late autism diagnosis and additional diagnoses imposed upon them.
2. *People-pleaser* - identified the negative effects of appeasing the needs of others.
3. *Underneath the mask was the abuse* - exposed the extent that the participants endured to conceal SAV.
4. *But was it abuse? I never said no* - demonstrated the participants questioning if they had experienced SAV because they did not attempt to stop it.

Refer to table 3 in section 4.5.

#### **4.2.4 Rape culture: The reality beyond the myth**

This superordinate theme expelled the myth that rape culture does not exist. It has five subordinate themes:

1. *Sshhh! Taboo of a male being raped* - highlighted that men can be susceptible to SAV by men and/or women.
2. *Loss of empowerment and control* - signified that people may abuse their positions of power and trust to disempower their victim.
3. *Sexual objectification* - typified the way individuals are sexually objectified to meet the needs of the perpetrator.
4. *Blurred lines: This is Normal - Isn't it?* - demonstrated the confusion of SAV because it was normalised by those in positions of trust.
5. *Victim-blaming* - portrayed the reasoning as to how each participant initially blamed themselves for experiencing SAV.

Refer to Table 4 in section 4.6.

#### **4.2.5 Specialist support services: Where are they?**

This superordinate theme emphasised the lack of specialist support and disjointed support services for autistic survivors of SAV. It has five subordinate themes:

1. *Counselling isn't for me* - established that professionals supporting autistic survivors of SAV lacked the skills required to meet their needs, and highlighted the implications for an autism diagnosis at the outset of therapeutic intervention.
2. *Retraumatization* - highlighted that those providing therapeutic support may unintentionally retraumatise their client, and increase their self-harm and suicidal ideation.
3. *I don't understand my emotions: Do you?* - portrayed the difficulties of each participant in understanding and effectively expressing their emotions.
4. *Communication misunderstandings* - revealed the difficulties experienced by the participants and their therapists, and the ways in which incorrect interpretations affected treatment.
5. *The mental connection is the most important* - highlighted the significance of mental connection to aid the recovery of SAV.

Refer to Table 5 in section 4.7.

#### **4.2.6 The importance of sex education for autistic people: The missing pieces?**

This superordinate theme highlighted the significance of suitable SE for the autism population to aid their sexual safety. It identified suitable topics to be included in current SE programmes conforming to modern-day society. It has three subordinate themes:

1. *A lack of sex education* - revealed that each participant had either no SE or it was limited and it did not meet their needs.
2. *Social media and online dangers* - exposed the dangers of technological communication for people with social and communication difficulties.

3. *What's missing?* - highlighted the subjects that were missing in SE programmes for autistic individuals.

As previously mentioned, this is not comparative research but similarities and differences are drawn-out from the data collection of the autistic participants, and the literature review regarding the general population. A main aim of this research was to gain knowledge of the implications of SAV within the autism population, and to examine why they may be vulnerable. Excerpts taken from the participant's interviews are presented, permitting the reader to ascertain my interpretation of the sense making process.

Refer to Table 6 in section 4.8.

## 1. The bleeding edge of autistic pain

**4.3 Table 1: Superordinate theme and related subordinate themes**

Subordinate theme	Daisy	Elijah	Thom	Gwen	Amy	Elsie
I am so utterly vulnerable	✓	✓	✓	✓	✓	✓
Coping mechanisms	✓	✓	✓	✓	✓	✓
The dissociated-self	✓	✓	✓	✓	✓	✓

### I am so utterly vulnerable

Every participant perceived themselves as vulnerable:

...as autistic people we are very vulnerable. We do tend to be subject to abuse. We quite often don't recognise it as abuse, and anything that gets attention to *that* is a good thing: ...I am so utterly vulnerable that it is very difficult not to take advantage of

me: It's probably what was picked up on by my abusers... the fact that I was already sexual... it made it easy for them. I was a *gift*. (Thom)

Thom emphasised 'that', suggesting that generally abuse goes unrecognised and it needs to be addressed. He was also acutely aware that he was sexually vulnerable and his abusers sensed this and he reflected. Thom shielded his abusers and justified their behaviour as he metaphorically referred to himself as a 'gift'. The emphasis on the word is indicative that he was open to exploitation. He perceived himself as 'already sexual' and he paused knowing that he was easy prey.

The fact that I was abused is not necessarily relevant to... anything as much as the autism is: ...I would still have been vulnerable. I would still have been manipulated. I would still have got into abusive relationships later on because I'm vulnerable. I'm fundamentally vulnerable that's who I am. (Thom)

...I feel like [vulnerable to abuse] because there should be more in place for autistic people to feel safe, to feel they're accepted. (Amy)

Thom perceived being vulnerable as an inherent part of his identity and characteristic of autism. Similarly, Amy felt vulnerable because of being autistic, and she recognised that generally autistic people are at risk.

Likewise, Elijah and Gwen felt susceptible to SAV due to the symptoms of autism:

[Vulnerable to abuse] Yes. I'm not good at... body language and understanding people. (Elijah)

I was *quite* naive and less likely to talk to people because I struggled with communication. (Gwen)

Elijah and Gwen acknowledged that their communication difficulties fed into their vulnerability. Elijah lacked the skills to understand the intentions of others positioning him sexually vulnerable. Gwen emphasised 'quite' referring to her naivety suggesting that she was vulnerable due to lacking verbal fluency.

In my teens I was quite vulnerable. If any guy gave me attention I'd be like *ok he likes me that's fine*. (Daisy)

In the same context as Gwen, Daisy used the word 'quite' referring to her vulnerability.

...as someone who's vulnerable, especially with the mental health condition that I have. (Elsie)

Elsie had a history of attempting to take her life and self-harming because of her poor mental health impacting upon her vulnerability.

### **Discussion: I am so utterly vulnerable**

This subordinate theme was interesting because each participant recognised that they were vulnerable individuals. There is a large amount of literature addressing autistic vulnerability to risk. In contrast, there are limited research publications regarding autistic sexual vulnerability although it is highlighted in the grey literature. Cazalis et al. (2022) deem that autism heightens women's sexual vulnerability. Equally, autism may be a factor in the sexual vulnerability of males. The participants in this research identify that their vulnerability was associated to autism itself. This concurs with the growing literature which has previously overlooked that autism can be traumatic for an individual (Au-Yeung et al., 2018; Cassidy et al., 2018; Gravitz, 2018).

Difficulties in social communication and regulating their emotions can further traumatise autistic individuals (Hoover, 2015). The symptoms of autism and their environment may expose them to trauma related to sensory sensitivity (Kerns et al., 2022). Children with predominant autistic traits and social awareness difficulties may be at an increased risk of abuse, interpersonal and multiple victimisation (Codina, Pereda and Guilera, 2022; Roberts et al., 2015), which was the case for each participant in this research. Their communication difficulties and inability to decode body language or decipher the intentions of others exposed them to SAV. Communication is considerably more than verbal expression comprising non-verbal cues, reading facial expressions, intonation, bodily movements, posture, and proximity. Body language emphasises one's feelings and non-autistic people are generally able to read them. Contrariwise, autistic individuals may find it difficult to understand the desires and beliefs of others (Broekhof et al., 2015) and this concurs with the findings in this research. Lawson (1998; 2005) took spoken language literally positioning him sexually vulnerable as a child because he believed that he had to do what his abusers said. The participants did as they were told by their perpetrators without resistance as they deemed that it was acceptable because if it was not, they would not be asked to do it. Thus, highlighting their trust in others and difficulty in recognising risky behaviours.

Non-autistic people are not faced with the added sexual vulnerabilities accompanying autistic individuals because they are not affected by autistic symptoms. Vulnerable individuals may not be able to protect themselves from harm (MENCAP, 2022) compared to those who may be better equipped with the skills to foresee potential danger.

## Coping mechanisms

Each participant engaged with coping mechanisms that were mainly unhealthy and addictive including substance misuse, promiscuity and pornography. Daisy, Gwen, Amy and Elsie attempted to take their lives:

*...I couldn't cope. I attempted suicide twice: I don't think I fully intended to want to kill myself. I just wanted all the noises to stop... I went a bit wild. It was probably a combination of everything. I was living wildly and in the space of a year and a half I was getting drunk. I was on weed. I did a little bit of cocaine... (Daisy)*

Daisy emphasised 'I couldn't cope' and she tried to take her life. 'Fully' suggests that she did not particularly want to end it, but to empty the clamour of disturbances in her head. Daisy emphasised 'everything' summing up the experiences of her life generally.

*The way I was able to process it, I went angry... I went into a depressive state. (Daisy)*

Daisy evoked emotional negative responses and she reflected upon her anger. Although anger is a negative emotion, it can also be a coping mechanism.

*I do repress quite easily and I don't want to touch it: ...my friend committed suicide: I really oppressed a lot of... trauma. (Elijah)*

Contrary to Daisy, Elijah blocked out much of his trauma. Possibly, he had mistakenly used the word oppressed; suppressed or repressed makes better sense. Trauma and

the loss of his friend exacerbated his grief and anger, and he channelled his energy into pornography:

...porn addiction did become a problem: I started to become interested in BDSM kinda porn which I think might've stemmed from the abuse: It became really frequent and it was stopping me doing other stuff. (Elijah)

Elijah acknowledged his problematic 'porn addiction' originating from his experiences of SAV which was so obsessive that it affected his life. He recognised his dependency which is in contrast with the other participants who did not refer to self-harming as addictive, but it is possible that they were addicted at the time of abuse.

I was quite traumatised early on by something and I don't know what: Yeah yeah yeah yeah whether that's just the autism or whether there was some, you know, some car crash or whatever that I blanked out of my memory... [sigh]. (Thom)

Thom was unable to recall early trauma because abuse can impact upon an individual's ability to retain and/or process information. He repeated 'yeah' which could be related to anxiety and attempting to reduce it. He delved back to his early childhood and tried to reason if his trauma was due to being autistic or something that he had blocked out. Thom did not have an autism diagnosis until late adulthood; therefore, the likelihood was that the trauma related to what he metaphorically referred to as a 'car crash', indicating a chaotic or disastrous situation he may have experienced. He reflected, breathed deeply and exhaled. His sigh may signify an expression of sorrow. Thom reflected upon his self-worth:

*In a weird way* the abuse hasn't caused as much psychological trauma as you might think. Even at eight I was beating myself up... my reading wasn't good enough. My writing wasn't good

enough. ...the fact that somebody *wanted me*... even at eight. Even though they only wanted me for what they could do to me, or what I could do to them. In a weird way that actually kind of helped... because I've got no self-worth. If someone else thinks I've got worth that'll do. I'm not good enough anyway but I'm good enough to do this. ...in a really fucked up kind of way... the abuse *probably* made me feel slightly better about myself psychologically... although it didn't... that's pretty fucked up isn't it... [sigh]. (Thom)

Thom emphasised and repeated 'in a weird way' suggesting that the abuse is a form of validation. He recognised this as a positive emotion, yet acknowledged that it is 'wrong' to feel that way and indicative of other forms of abuse. Inwardly, he recognised that it was unusual for his experience of abuse to be helpful. He emphasised 'wanted me' referring to his abusers and then paused. The silence gave Thom reflection time and his figurative use of language evidenced that he had punished himself as a child. He endured the abuse and accepted it because of needing to belong. The context of Thom's words 'that'll do' emphasised that because he did not have any self-worth, the abuse was not as bad as expected because it gave him the quality of feeling good enough for something. He knew his logic was disturbed and conflicted with certain expectations of the norm. Thom contradicted himself and emphasised 'probably' demonstrating that to an extent he was unsure if the abuse made him feel better, but then acknowledged that it did not. Repeating 'fucked up' highlights the extent of the psychological damage that was possibly caused by the abuse. Thom fell silent which helped him to process his thoughts. He sighed which could be interpreted as grief and/or weariness.

There was a palpable feeling of sadness and emptiness as Thom reflected:

It's it's it's just feeding into this worthlessness. It's constantly feeding in, constantly reinforcing that... doesn't matter what I do, I'm only useful for one thing, so I might as well give up really. I'm never going to be good enough in any other area so what's the point..... erm..... [yawn]..... that stuck with me for a long time, even in the period of time I wasn't being abused..... What's the point [sigh]..... (Thom)

Thom demonstrated high levels of introspection and self-reflection whilst considering his self-worth. He repeated 'it's' possibly referring to his feelings of inadequacy. He repeated 'feeding' and 'constantly' indicating that it persistently fed into his lack of self-worth and no value as a human being. 'Reinforcing' demonstrated that it strengthened his perception that there was nothing he could do to change anything. He paused several times and expressed that no matter how hard he tried he was only useful for being abused. He was unable to change the way he felt because he had the same feelings whilst not being abused. He repeated 'what's the point' demonstrating that he questions his existence as it is pointless. Thom reflected and yawned, and it seems that he had feelings of depression and a sense of hopelessness and/or weariness.

I've had very negative outlets for pain and grief: They're not particularly healthy but it got me through: ...lots of self-harm and binge and purging [laugh]: I drank a lot. I took drugs because I just wanted to be numbed from it all: Making a joke out of things always helps because I do that a lot [laugh]. (Gwen)

Gwen was aware of engaging in risky behaviours which helped her through her misery. She laughed and this emotion could be related to easing her pain. 'Numbed' symbolises the need to deaden the pain from her trauma. Throughout her narrative Gwen used gallows humour, a form of dark wit considered to be a healthy coping mechanism, and used by individuals experiencing trauma (Maxwell, 2003). Humorous

talk may be deemed serious talk that can enhance the understandings of lived experiences in risky situations (Parkhill et al., 2011).

I've dealt with it in my own little bubble and I make little jokes. I kinda make a mockery of my life [laugh]. Whenever I make a joke of how sexually experienced I am, it's a funny joke to me because so what I've been having sex since I was six so try and beat that [laugh]. Whereas everyone else is like *what?* They're not used to it. So, when they start asking, questioning and trying to probe into my life, it turns into a real reality for me and I can't handle that. I don't know how to process my life. I leave it at jokes. Its happened. There's nothing I can do about it so why am I revisiting it. (Gwen)

Gwen's metaphorical language 'bubble' suggests shielding herself. A self-protective bubble can benefit vulnerable individuals needing protection because it provides a safe space from people or objects perceived as threatening. She ridiculed her life and made fun of her trauma because it protected her from her reality. 'So what' indicates that she did not care and/or what she had experienced was unimportant. This is contradictory because 'I can't handle that' suggests that she did care, but it was painful to revisit. Gwen demonstrated a competitive side to her 'try and beat that' referring to having sex aged six. Her use of irony and self-deprecation put people at unease. She possibly intended to use shock value as a mechanism to stun people. She emphasised 'what' suggesting her success in provoking a reaction from those delving into her life. Gwen reconciled with her experiences and decided not to go back there because she could not change it. Although laughter is a healthy emotion, it also has a dark side (Szameitat, Szameitat and Wildgruber, 2022) as evidenced by Gwen.

**Reflective box**

Gwen's description elicited a strong mix of emotions in me regarding my position as a mother. Whilst referring to having sex aged six, I physically reacted and I felt nauseous. It conjured up images of my own children when they were small and what

if it had been them? The thought of them being sexually abused filled me with horror. I felt anger and an intense loathing towards her abuser. My maternal instinct was to hug her but this seemed inappropriate as she was laughing. As she joked, I felt the sadness that she seemed to be masking.

I had to deal with all that reality crashing in that he was the one holding all of that. (Gwen)

The death of Gwen's best friend impacted upon her coping mechanisms and her figurative use of language indicates her world falling apart.

...took overdoses and I self-harmed: Anything to get rid of this numbness that I felt inside: I felt so scared that I just wanted to end my life at the time. It's just so *painful*..... Five [overdoses] but they were small ones because I wanted to get rid of the pain..... (Amy)

In contrast to the participants who self-harmed to numb their pain, Amy self-harmed to relieve her numbness. Possibly, her feelings of emotional numbness provided an exit to reducing distress (Hochschild, 1983). Amy was afraid and the only way she could egress was to take her life. She emphasised 'painful' and fell silent. The overdoses were small-scale, and similar to Daisy, it seems that it was a cry for help.

I used to jump in front of cars...: I tried to crash my car...:  
...changed my method of suicidal attempts, it became more overdoses... (Elsie)

Elsie did not succeed in taking her life but she remarked that she had been hospitalised "three times".

...I was too fragile. Erm if I was left alone I did stuff, I would cut, I would plan, I would get upset, I'd be found in my bedroom crying and stuff like that. I was highly emotional. (Elsie)

Elsie felt emotions deeply and she was at breaking-point. Crying exemplifies her vulnerability and it is a natural response to trauma. It is a common form of human expression which can help the psychological and physiological well-being of the individual who is crying (Hendriks et al., 2008).

### **Discussion: Coping mechanisms**

This subordinate theme highlighted the pain experienced by each participant because of their exposure to SAV affecting them psychologically and physiologically. Survivors of SAV may engage in self-injurious behaviour as it can be used to express and manage emotional distress (NHS inform, 2020). Self-harm can be experienced by the general and autistic populations. There is considerable correlation between CSA and varied forms of self-harm (Miranda, Mangaoil and Rungduin, 2023). This subordinate theme exposed the extremities that autistic individuals underwent to eradicate their pain. Attempted suicide and self-harm were described by the participants. Deaths by suicide are a worldwide public health challenge in the general population (Favril et al., 2023). There is a strong association between SAV, attempting suicide and mental health problems which is complex (Carlsson, Owen and Rajan, 2022). Brokke et al. (2022) acknowledge that trauma and particularly SAV increases the risk of individuals attempting to take their own life. A greater proportion of people attempt suicide due to their exposure of SAV compared to those who are unexposed to it (Carlsson, Owen and Rajan, 2022). However, the prevalence rates of suicide are higher for the autism population compared to non-autistic populace (Kirby et al., 2019). This is disturbing, but unsurprising considering that autistic individuals are highly susceptible to SAV compared to non-autistic people who do not experience autistic sexual vulnerability.

Autistic individuals are at greater risk of attempting suicide compared to non-autistic people (Kirby et al., 2019). However, there is a gap in the literature addressing the prevalence rates of suicide for autistic survivors of SAV. Richards et al. (2019) acknowledge the growth in literature concerning autistic adults being at an increased risk of suicidal thoughts and either planning or actually taking their own lives. This concurs with the research evidence by O'Halloran, Coey and Wilson (2022) claiming that one in four young autistic individuals have suicidal ideations and almost one in ten try to take their life. The research indicates that people with PTSD have a heightened risk of suicidal ideation and Fox et al. (2021) state that up to 54% of people take their life as a result of PTSD. The most common cause of PTSD is related to SAV (Campbell, 2002; Chivers-Wilson, 2006). Survivors of SAV are thirteen times more likely to attempt suicide compared to those who have not been victimised (Kilpatrick et al., 2000). With these prevalence rates in mind, it is plausible to consider that autistic survivors are potentially treading on uncertain and dangerous territory. The consequences of SAV go beyond the act itself and the trauma needs to be effectively managed.

Little attention has been given to self-harm, suicidal thoughts and behaviours addressing *why* there are high rates of suicidality in autistic individuals (Cassidy et al., 2018; Cassidy et al., 2020). Cassidy et al. (2018) conducted a study exposing that compared to the general population and other clinical groups, suicidal thoughts and behaviours and rates of suicidality are intensified in autistic adults. There has since been a shift in understanding the reasons and the contributing factors relate to camouflaging; alexithymia; repetitive thoughts; and lack of support (Newell, 2021). This concurs with Cassidy et al. (2018) as they identified risks unique to autism

including autistic traits; autism diagnosis; camouflaging autism; unmet support needs; demographics; and unsatisfactory living arrangements. There is an overlap of suicidal risk markers in both the autistic and non-autistic populations which may be due to depression or unemployment (Cassidy et al., 2018).

Cassidy et al. (2020) recommend future research addressing self-harm and suicide for autistic people. This is important given the prevalence rates of suicidal ideation in autistic individuals is one in four and disturbingly, virtually one in ten attempt suicide (O'Halloran, Coey and Wilson, 2022). 66% of individuals diagnosed with AS have considered suicide and 35% had planned or attempted it (Cassidy et al., 2014). It is important to consider that non-suicidal self-injury (NSSI) and suicidal behaviour can be perceived as an addiction to self-harm (Blasco-Fontecilla et al., 2016). NSSI is significantly more likely to affect autistic adults compared to the general population (Cassidy et al., 2020).

### **The dissociated-self**

Each participant dissociated from their trauma which is demonstrated in various ways.

Daisy, Thom and Gwen disconnected from their own body:

Anal [rape] was extremely painful but I just took myself away from him, the scenario: I let my mind go elsewhere so it's just my body there. I'm a spiritualist so I control my energy. (Daisy)

...the physical pain of abuse you can shut it out: The psychological damage you don't notice really at the time. ...it's as if it's happening to someone else: While it's happening, you put yourself in a different place: When it's over, you don't think about it. (Thom)

It's almost like I *drifted*. I dunno kind've like I wasn't in my own body. It went back to like when I was younger cus I know the reason I blanked it out was because of the pain. (Gwen)

Similarly, Daisy, Thom and Gwen referenced 'pain'. To manage it, they separated their mind and body comparable to an out of body experience. It was a powerful coping strategy and typified as a dissociative episode. For Thom:

...it was like I was watching porn. It wasn't me... that was the centre of the attention. It wasn't me that was performing various acts. I was watching somebody else: It was almost like an out of body experience... I suppose it's a defence mechanism. You're going through something that's not pleasant. You distance yourself from it, tell yourself its fine particularly when it's physically uncomfortable... (Thom)

Dissociation can be linked to how a traumatised person observes what is happening around them instead of feeling the pain. Thom's dissociation seemed surreal as it was characterised by pornographic imagery. He compared himself to an actor indicating that his abuse was happening to someone else. Akin to Daisy, Thom dissociated from his physical pain putting himself at one remove. He recognised it as avoidance and seemingly he was in denial.

Amy and Elsie dissociated:

I've blocked it all out because that's the only way I cope. (Amy)

...something had triggered it, like a memory cus after once I'd started letting all, letting it all come through, and actually acknowledging that this had happened to me because I got through uni with being fine you know. I'm good, I'm strong, nothing happened, nothing happened and just literally forgot about it, put it in the back of my mind and just got on, but letting it come through like that meant that I was having flashbacks every now and then. (Elsie)

Elsie experienced an emotional reaction to a resurfaced memory. As it filtered through, she acknowledged that she had been abused. Her 'flashbacks' and dissociation were 'triggered' by something that reminded her of the trauma. Elsie's vocabulary suggests that dissociation was a coping mechanism:

...I will try and tell my story. I'm going to be jumping and starting timelines: Maybe it's because I'm trying to avoid a certain section [laugh]. (Elsie)

Elsie dissociated during her interview and she is aware of it because she acknowledged that she would bypass specific parts of her story. She nervously laughed signifying that she felt confused, embarrassed, and/or discomfort at confronting something that she had initially repressed.

Daisy, Elijah and Amy's language was interesting as linguistically it illustrated dissociation. They referred to the abuse in the second-and-third-person which is a form of depersonalisation:

To keep myself sane was to go to a safe place mentally. I had to take myself out of the situation. The body was there. The body suffered the abuse: It's a way my body decided to cope with PTSD: He got annoyed with it and just took it anyway [anal rape]: ...*destroyed*, the innocence. (Daisy)

The part of the body that tends to be the most painful is the anus. (Elijah)

Daisy referred to 'the body' and not 'my body' indicating depersonalisation, and that her body coped with the trauma demonstrating dissociation. She emphasised '*destroyed*' symbolising her loss of innocence. 'The' relating to innocence meant that she had depersonalised it as she did not refer to herself in the first-person. Similarly,

Elijah referred to himself in the third-person, and dissociated from the pain evidenced by 'the body' and 'the anus' signifying that it was his body that suffered the abuse and not himself.

There was a palpable feeling of hopelessness as Amy described her feelings. Her use of words and pronouns demonstrated dissociation:

I felt really numb. I still feel it today. I feel like there's no support and there's no turning back, and you feel like you are a failure. You feel like they [rapist] did this to you. You feel powerless and you feel *undignified*, and you feel, you feel like you're just living and you can't you can't just be yourself. They they're in control, they they they they took this away from you, so it just makes you feel like you're worthless..... [sobbing]. (Amy)

Amy's excerpt was emotive and she outwardly displayed her emotions through sobbing, demonstrating the intensity of her pain. 'Blocked' and 'numb' symbolises dissociation and even now she dissociates. She referred many times to the second-person pronoun 'you' and the third-person pronoun 'they'. She repeats 'you feel' symbolising the depth of emotional intensity. She felt hopelessness and she is devoid of power to change it. She emphasised 'undignified' suggesting that her dignity had been crushed. She was humiliated by her experiences and they were unwittingly inflicted upon her. Amy was merely existing as she was unable to be her authentic self because she believed that the rapist still had control. She paused, and the silence was broken by her sobs as she reflected on the effects that the rapist had on her. I could feel her desperation and helplessness as she felt 'worthless' and I sensed that she thought she was beyond help.

There was a crossover between Amy's use of language as she expressed herself in the first-person and then the second-and-third-person "I felt really numb, I still feel it today..." and in the same response switched to "...you feel like you are a failure...". Whilst talking about her feelings of numbness, she referred to herself in the first-person but when she talked about being a failure, she was unable to continue to do that. She cannot think of herself directly as a failure, in a similar way to being unable to use the word rape regarding her baby. She then spoke in the first-person and emphasised 'they took away my whole life' and acknowledged the reality of her experience as she had nothing left to live for. She explained:

...I was thinking that's my baby. That's what I had to go through [rape] [sobbing]. ...I was getting used to the idea of becoming a mum and I was going to do everything I could to protect that child, and it broke me into pieces..... (Amy)

Evidently, Amy is grieving the loss of her baby and motherhood. 'That's my baby' and 'protect that child' suggests that she referred to the child as her baby, and the child of the rapist, the former being the acceptance of motherhood and the latter being her dissociation of rape. She felt broken and reflected in silence.

#### **Reflective box**

Amy's whole demeanour was that of excruciating emotional pain which I could feel as she sobbed throughout her description. I felt helpless as she sat in the chair, hugging her body and rocking back and forth. Tears streamed down her red cheeks mixing with her mucus. I passed her tissues and she attempted to wipe her eyes and runny nose, and the saliva that dribbled from her mouth. I held her hand in an attempt to acknowledge that I was in the moment with her. It was poignant as she looked me in the eyes and gently nodded her head. She too gently squeezed my hand as we made an emotional connection. Emotion work is concerned with emotions whilst making a connection with people and being in touch with others (Cataldi, 1993). She stuttered as she repeated the word 'they' four times in succession. To have been a part of this experience exemplifies 'thinking' and 'feeling' rape combined with her despair and the emotional aftermath of a devastating criminal act by one person on another.

The use of the second-and-third-person pronouns exemplified the extent of the physical and psychological abuse experienced by the participants, and captured the essence of how they depersonalised it. Five participants referred to autism as if it was an appendage:

I don't know whether that's just me or the autism. (Daisy): People with autism... (Elijah): The autism... (Thom and Elsie): Having autism... (Amy)

This is in contrast to accounts from autistic authors such as Sinclair (1999), who first documented the rejection of first-person language because he identified autism as a feature of himself as an individual. Similarly, Botha, Hanlon and Williams (2023) argue that the use of language has implications for autistic individuals including stigmatisation, dehumanisation, and violence. It could also be related to an autistic trait recognised as pronominal reversal whereby some autistic individuals have a tendency towards referring to themselves in the second-or-third-person pronoun (Sterponi, de Kirby and Shankey, 2015).

### **Discussion: The dissociated-self**

This subordinate theme revealed dissociation as an effective coping mechanism for the participants, and non-autistic people may also dissociate. Dissociation is commonly linked to SAV, and higher levels of dissociation are related to self-harm, suicidal thoughts and attempting suicide (Brokke et al., 2022). Reuben, Stanzione and Singleton (2021) conducted a study to understand why autistic individuals are more susceptible to trauma and how they are affected by it. They acknowledge that IPTs are reported by a large number of autistic adults including SAV and are commonly related to post-traumatic stress and dissociation. The study comprised six hundred

and eighty-seven autistic adults who had self-identified. They completed an online survey, and the findings revealed that 72% of the participants were exposed to sexual assault; unwanted sexual experiences or physical assault; 44% reported PTSD including 50% having IPT; 93% experienced mind-based dissociation at a high level; and 32% had body-based dissociation at high levels. Jacobs-Kayam and Lev-Wiesel (2019) also found that dissociation is a central coping mechanism for survivors of SAV and described it as feeling adrift to protect themselves. There are links between dissociation, masking and late diagnosis impacting upon mental health. Fundamentally, there seems to be a connection between masking and emotion work which is profound. As some of the participants began to remove their masks, it enabled them to get in touch with their feelings, and they were able to articulate their experiences either verbally or non-verbally. Interestingly, as they had dissociated, they seemed to be able to reconnect with themselves.

## 2. My dysfunctional family came at a cost

**4.4 Table 2: Superordinate theme and related subordinate themes**

Subordinate theme	Daisy	Elijah	Thom	Gwen	Amy	Elsie
My dysfunctional family and me	✓	✓	✓	✓		✓
All I need is love	✓	✓	✓	✓	✓	✓
I can't tell you - it's my secret		✓	✓	✓		
The ripple effects	✓				✓	✓

### My dysfunctional family and me

Each participant, except for Amy, was raised in a broken family, meaning that they were unhealthy and/or their family unit was damaged by divorce or death:

Mum and dad split up when I was five. (Daisy)

...mum died when I was thirteen after battling with terminal cancer. (Thom)

...I didn't know I was in danger. I just knew that my dad was shouting which meant my mum was in danger. (Gwen)

[Mum] ...she got fibromyalgia: ...a chronic alcoholic: [Step-dad] ...my mum's dependent upon this man, she's in love with this man, she needed this man. (Elsie)

Elijah and Elsie were raised by their grandparent/s:

...my family breaking down, moving in with my grandmother... (Elijah)

... she raised us alone [mum]. My dad left us er god when I was in year one: ...she didn't really raise us as much as my grandparents. (Elsie)

There are similarities within the participants' families regarding mental health issues, addiction, physical health problems and evidently, a culmination of oppression. Daisy, Gwen and Elsie's dads had mental health problems as did Gwen and Elsie's mums. Daisy's dad and Elsie's mum were alcoholics. Daisy, Thom, Gwen and Elsie's mums experienced poor physical health and demonstrated below:

[Dad] ...he's got PTSD from being in the army. (Daisy)

...dad's ex-army, and he's suffering quite badly at the moment with PTSD. (Elsie)

Presumably, Daisy and Elsie's dads developed PTSD as they witnessed trauma whilst serving in the armed forces.

[Mum] ...she's got a bit of bad mental health. [Dad] ...he's mentally ill. He has bi-polar and struggles with depression.  
(Gwen)

We sectioned her cus she couldn't mentally cope. (Elsie)

Elsie's reference to 'we' indicates taking responsibility towards her mum as this is in contrast to 'she' or 'they sectioned her'. The following excerpts exemplify the physical health needs of Daisy, Thom and Elsie's mums and how they shouldered their needs:

I grew up way too quickly but I don't think some of it's down to the abuse. Some of it's my dad being an alcoholic, my mum being quite ill so I had to grow up very very quickly to be able to care for both of them. (Daisy)

Daisy was deprived of her childhood and she associated it to her caring responsibilities for both parents. This role reversal, known as parentification, consists of two types and is classified as instrumental and emotional. Instrumental parentification involves practical caregiving and emotional parentification is emotional support (Burton et al., 2018).

...didn't get on with my dad. Never did. Wouldn't have gone to him to pour water on me if I'd been on fire..... (Thom)

Thom did not have a relationship with his dad. He fell silent after his use of figurative language and he reflected upon his hatred for him. Hatred is a powerful negative emotion and Thom was consumed with it. It probably resurfaced horrible memories that he had repressed because this is his only mention of his dad throughout his narrative. These adverse feelings possibly developed in childhood, and the reasons

why he hated him are unknown. Possibly, after his mum's death, he was raised by his dad who was abusive.

Gwen's relationship with her mum is a good example of emotional parentification:

[Mum] ...she has no one else so I've had to look after her: ...because she was abused, I've kind've been her rock: She can just spew whatever she likes. When I was seven she told me that she wanted to go to sleep and not wake up. Like as a seven-year-old hearing that, but as a mum she didn't *mean* to say that. She just had no one else to say it to. (Gwen)

Metaphorically, Gwen refers to herself as her mum's 'rock' indicating that she is strong, dependable and supportive. This is emotional parentification and she was her mum's confidante and emotional caretaker from as young as seven. The idiom 'spew' indicates that her mum went beyond her limits whilst informing Gwen about her problems. Gwen's earlier comment about her mum's mental health being a 'bit' suggests that it is mild. This is contradictory because she then refers to not wanting to 'wake up'. She emphasises 'mean' suggesting that her mum did not intentionally intend to do so. Possibly, her mum has passive suicidal ideation as there was no mention of suicide.

#### **Reflective box**

I understood how difficult it must have been for Gwen's mum because of the abusive relationship she was in, and also her mental and physical health problems. However, I felt a sense of ambivalence towards her. Gwen was her best friend and I felt frustrated that she burdened her seven-year-old child, particularly confiding in her that she wanted to go to sleep and not wake up. I was surprised that Gwen had the cognitive ability to understand at such a young age the meaning of her mum's words. Gwen's narrative triggered memories that I had repressed for twenty-five years. Although I had not experienced what Gwen's mum had been through, I previously had difficulties in my life. My husband commuted long distances to make ends meet for our family and at times it felt like I was a single mum. The stress of raising four children under the age of six and the complexity of throwing autism into the mix took its toll on my physical and mental health. I 'burnt out' and I was physically and

psychologically exhausted. I recall wanting to go to sleep and not wake up. I was in a different position to Gwen's mum as I had a loving family and friends to support me through those dark days. I knew I had to be strong and keep going for the sake of myself and my children's well-being. I was able to get the support I needed; thus, highlighting the importance of healthy connections.

It is important to include my experience because as much as it pains me to recall that period of my life, I cannot expect the participants to share their intimate experiences if I am not prepared to do the same. Incorporating my experiences into this research has been cathartic. I feel fulfilment as I have effectively moved forward. This arouses hope for individuals experiencing trauma because all too often, they can and do, recover.

Some participants either observed or experienced physical and/or psychological abuse targeted towards family members or themselves. The following excerpts demonstrate the dysfunctionality of their families:

If my parents were still together, I was living in [place name] I don't think I would've met the guy [rapist] in [place name] or I would've been dating someone else. (Elijah)

Elijah held his parents culpable for his experience of SAV.

[Dad] He was more physically abusive than sexually abusive. He'd abuse my mum. I'd try and get in the way of it because my mum is my mum. You always try and protect her and then obviously it would have a backlash on me. (Gwen)

Gwen attempted to protect her mum but there were repercussions as 'backlash' suggests that her dad reacted in a strong and negative way towards herself.

[Step-dad] ...he got lazy. ...my mum was already working near enough fifty to sixty hours a week. (Elsie)

Elsie's step-dad did not financially contribute to the family and the onus was on her mum. She lived an impoverished lifestyle and the family's financial circumstances were poor, and they treated her unfairly for their own benefit:

They trolled my money: ...I was working as well. Erm they kept my money: ...provident loans those things, they'd taken one out in my name: ... a grand that was left on that loan, because it had so much interest and months of them not paying, and so yeah I had to pay that: ...it was taken out in my name, that was horrible: ...the guy let her. Cus one of those few people he had to come round round every week to collect the money from you, the fact he'd let them do that, that was another bit... (Elsie)

Elsie's mum and step-dad exploited her financially which is a form of coercive control. They used her personal and/or financial information without permission which is identity theft. Subsequently, she took responsibility for their debt. As she reflected upon the role of the debt-collector, there was a palpable air of horror. 'Horrible' is a negative emotion whereby Elsie disliked what had happened, and she felt doubly betrayed as the debt-collector was deceptive. Her kindness was also taken advantage of:

...I'm starting to learn to drive. It's going to be a while but I'll buy it now. You guys can use it [car]: They wrecked this car and I mean wrecked it to the point where there were flies, maggots, all growing up the carpet cus it was water logged. (Elsie)

Elsie's plans of helping her mum and step-dad backfired as she repeated 'wrecked' symbolising that her car was damaged so badly it was unfit for purpose.

### **Discussion: My dysfunctional family and me**

This subordinate theme took me by surprise as I had not initially considered the implications of living within a dysfunctional family. It highlighted the dynamics of an adverse family environment that came at a high cost to the participants. They witnessed ongoing conflict affecting their psychological well-being. Children from dysfunctional families are at an increased risk of SAV (Al Ubaidi, 2017). There are

contributing factors that expose an individual to SAV due to growing up in a family that misuses alcohol, attempts suicide, or witnesses violent acts (Carlsson, Owen and Rajan, 2022).

A dysfunctional family is one in which conflict and instability are common. Parents might abuse or neglect their children, and other family members are often forced to accommodate and enable negative behaviour. In some cases, dysfunctional families can be the result of addiction, codependency, or treated mental illness. (King University, 2017, para. 1)

The above definition captures the experiences of the participants in this research. Autistic and non-autistic individuals experience the same effects of growing up in diverse family dynamics. They include some or all of the physical and mental characteristics comprising poor relationship boundaries; lack of affection; social isolation; trust issues; physical and/or psychological abuse; SAV; verbal abuse; economic abuse; loss of power and control; coercion; grooming; invasion of privacy; co-dependency; normalisation; unempathetic; criticism; mental health problems; PTSD; anxiety; depression; panic attacks; addiction; and substance misuse. The participants witnessed this behaviour and for Gwen and Elsie the abuse was targeted towards themselves. They were unable to recognise those features that were a consequence of their own abuse. Those residing within this type of environment can lead to family isolation due to restricted relationships (Al Ubaid, 2017). This could impede the opportunities to socialise and communicate with people outside of the family.

Society is by definition ableist; therefore, autistic individuals are already victims from birth as they are considered to be of lesser value because of their disability. From the

following perspective it is unsurprising that autistic people can be ostracised within society:

...whilst claiming 'inclusion', ableism simultaneously always restates and enshrines itself. On the one hand, discourses of equality promote 'inclusion' by way of promoting positive attitudes (some legislated in mission statements, marketing campaigns, equal opportunities protections) and yet on the other hand, ableist discourses proclaim quite emphatically that disability is inherently negative, ontologically intolerable and in the end, a dispensable remnant. (Campbell, 2009, p. 12)

Exclusion can be damaging, particularly for those who are vulnerable and marginalised. Kimberlé Crenshaw, a black American feminist who advocates for civil rights and a leading scholar of critical race theory, put it simply whilst speaking at a TED Talk:

... if you're standing in the path of multiple forms of exclusion, you're likely to get hit by both. (Crenshaw, 2016)

It was poignant as she exposed the tragic circumstances whereby socially marginalised people were oppressed and murdered by those in positions of power. To bring to life the reality of their experiences, she presented recordings of the victims stating the necessity for 'change' to stop the violation. She advocated the need to speak up for victims of prejudice. It is only by listening to the stories of marginalised and discriminated against people that we can get a glimpse into their realities. Giving them the chance to be heard is important because they are the experts of their own phenomenon enabling society to be informed about taboo topics.

The intersectionality of vulnerability and violent experiences differ based on social location (Colpitts, 2019). People living at the intersection of multiple oppressions tend to lack the resources enabling their safety and basic needs to be met, thus resulting in higher violence rates and underreporting of the crime (The New Jersey Coalition Against Sexual Assault) (NJCASA, 2018). The findings from this research concurred with those of Al Ubaidi (2017) who acknowledged the detrimental effects of living within a family environment that is consumed by toxicity:

Victimised children growing up in a dysfunctional family are innocent and have absolutely no control over their toxic life environment; they will have a lot of emotional scarring from repeated trauma and pain from their parents' actions, words, and attitudes. Ultimately, they will have a different growth and nurture of their individual self. (p.1)

In many contexts, children are defined by the way they are raised and intersectionality recognises the importance of family values and the influences it has on the dynamics of family members. Al Ubaid (2017) explains:

The definition of a family dynamic is the scheme of family members' relations and interactions including many prerequisite elements (family arrangements, hierarchies, rules, and patterns of family interactions). (p. 1)

It is worth considering whether the experiences of the participants in this research may have been different if they had lived within a well-functioning family. Well-functioning families are characteristically loving and supportive of their family and they are given autonomy, security, respect, belonging, connection and social influences spanning a lifetime (Thomas, Liu and Umberson, 2017). A blend of these characteristics can influence healthier mental well-being. These families encounter disputes but they tend to have the skills to overcome adversities. Dysfunctional families function under the

umbrella of oppression and disadvantage negatively impacting upon a person's self-esteem, confidence and mental health. Sexually abused children frequently live within this type of environment regardless of whether it is intra or extra-familial abuse (Martsof and Draucker, 2008). Autistic individuals may experience psychological effects if they are misunderstood by their family members. Misinterpreting the behaviour of autistic children leads to higher rates of exclusion within society (Perepa, 2019).

The participants in this research lacked autonomy enabling them to be of significance which detrimentally effected their mental health. This concurs with Turan et al. (2019) as they recognise that diverse settings can influence the mental and physical health of individuals due to intersecting forms of stigma. I considered the intersects between family dynamics and the symptoms of autism. There could be greater implications for the autistic population compared to non-autistic people whilst living within a dysfunctional family. This is due to the lack of boundaries and social rules as many of them may feel safer having certain boundaries and a good routine, which is likely to be lacking if it is chaotic.

No participant in this research referred to their parents noticing any autistic traits in them. This concurs with the grey literature whereby a common theme that emerged from the bloggers was that they lived in a dysfunctional family and autism was unidentified. This is possibly due to family members being immersed in their own problems and/or being ignorant to the symptoms of autism. It is worth giving attention to whether they would have experienced less trauma if they had lived within a well-functioning family. Autism is perceived as an invisible disability and possibly, it went

unnoticed as their families probably lacked the instinct to seek a diagnosis. Consideration deserves to be given to whether the symptoms of autism could be exacerbated by witnessing physical and psychological abuse.

This research elucidated the vulnerabilities of autistic individuals, and also their empathetic skills and resilience. Five participants resumed the parenting roles which is a common characteristic of living within dysfunctional families (Al Ubaidi, 2017). The Children's Society (2023) state:

By definition, a young carer is someone under the age of 18 who looks after a family member or friend who has a physical or mental health condition, or misuses drugs or alcohol. They may also look after brothers, sisters or elderly relatives too. (no pagination)

The instrumental and emotional parentification robbed some of the participants of their childhood and their own practical and emotional needs were neglected. There is plentiful literature addressing child carers in the general population but there is no research undertaken regarding autistic carers. This is concerning as this research exposes the caring responsibilities of autistic individuals. It is important to recognise the subtle intersects between autism, SAV and dysfunctional families.

### **All I need is love**

There is a distinct connection with the participants living in a dysfunctional family as they lacked love and support to meet their needs and therefore, attempted to seek it elsewhere. They were unable to fill the void that had been missing in their childhood, and they offered insightful reflections as they recognised their own risky behaviour:

I was bouncing from relationship to relationship because I needed to feel some form of love that wasn't from my family, and it was putting me into dangerous situations: I went through uw shit twelve different partners in the space of a year and a half. (Daisy)

Bouncing from relationships may symbolise a rebound and this was possibly Daisy's experience. Each relationship breakdown had been painful and her promiscuity during an eighteen-month period was possibly an attempt to feel 'love'. 'Uw shit' indicates that she surprised herself by the number of partners she had within a short period.

It's alright having sex with random people but... it... it's much better that love was one of the key driving factors to having sex, because having sex with a stranger might be fun, but as in my experience it can turn out to be dangerous. (Elijah)

Similarly, Elijah engaged in casual sex and whilst he reflected upon this activity which happened without conscious decision, he acknowledged that it was unsafe and love was the catalyst towards a healthier sexual experience.

I... had relationships with men and women... erm... er [sigh]... There were a lot of them... I'm not even sure that you can categorise them as relationships. They were purely physical, very short lived. I would bounce from relationship to relationship to relationship to relationship, erm... and that was that was a pattern for... the next five or six years. (Thom)

There was a palpable air of reflection as Thom considered the meaning of relationships. He sighed which could be interpreted as sadness, particularly as he was unsure if they were genuine. Thom bounced from relationships identical to Daisy, and had sex with countless people spanning several years. Although Daisy appeared shocked about the amount of people she had sex with, Thom was unfazed. It seems that he was a serial monogamist; attempting to fill a void in his life which was possibly a healthy connection.

I don't think any of the relationships were healthy but I don't think I deserved at that point, a healthy relationship. I'm not sure that I'd have known what to do with one if I had one because I'd never had one. So, it was almost as though I needed the relationships to be unhealthy to know what to do in them. I've never experienced anything else. So that was quite a painful realisation because that then made me think well I'm never going to have a healthy relationship because I'm not capable. (Thom)

Thom had low self-worth and/or feelings of inadequacy as he felt undeserving of being in a healthy relationship. He makes a link between his experience and what he was capable of. He locates this clearly as temporary 'at that point', showing his ability and belief in himself as capable of moving on from it. Thom's description of unhealthy relationships is embedded in his thought process. He is unable to recognise what would be different in a healthy relationship and would not know what to expect. This 'painful realisation' was a sudden awareness that this was true and Thom felt hurt by what he was missing.

Equally, Gwen bounced from relationships:

...I have a fundamental fear of being alone. It's probably because my dad hates me so I need to feel loved from someone [laugh]: I move on to new relationships quite quickly and if I don't, I feel like this broken toy again. I'm like no one's ever going to want me. I start to get really panicky and it really affects my mental health. (Gwen)

Although Gwen referred to having a poor relationship with her dad, it seems that subconsciously she craved his attention. Her laughter possibly concealed her sadness. She associates her dad's hatred towards her as the reasoning behind her many relationships. Gwen felt abandoned by her dad which impacted on her self-esteem, and to fill the void of not feeling his love, she engaged in numerous unhealthy

relationships. She is desperate not to be alone, and it seems that an abusive relationship is better than nothing. Her metaphorical use of language demonstrates the emotional damage she experienced, and this may contribute to her being unable to fulfil a healthy relationship.

I want to keep porn separate from actually is, love making.  
(Elsie)

[Boyfriend] He was being very sexual towards me and not wanting love and that's what I wanted. I wanted love. I wanted respect and I wanted to be loved because I wanted to fill the void.  
(Amy)

Elsie and Amy desired love. Even though Amy did not come from a dysfunctional family, she too was desperate for love and felt empty. Her boyfriend used her for his own sexual gratification and he had no desire for love. The repetition of wanting love highlights that Amy is lacking this basic human emotion, and unable to fill her feelings of emptiness.

### **Discussion: All I need is love**

This subordinate theme highlighted that the participants were sexually victimised from children into adulthood, and concurrent with the research evidence whereby it can span an individual's lifetime (Jacobs-Kayam and Lev-Wiesel, 2019; Roberts et al., 2015). The participants desired love as a child and adult exposing them to extreme risk. Although they were unable to forge a healthy emotional connection in romantic relationships, it seemed effortless engaging in physical sexual relations. This suggests that there is congruence between the vulnerability of autistic individuals' high prevalence rates of SAV (Brown-Lavoie, Viecili and Weiss, 2014; Griffiths et al., 2019). It also exposed the unconditional love that they did not experience. Love constitutes a

psychological connection and security. This was missing in their lives and to gain affection they attempted to fill the void and some became serial monogamists. Similarly, non-autistic survivors of CSA may become promiscuous to gain affection (Miranda, Mangaoil and Rungduin, 2023).

The findings from this research concur with the current literature regarding IPTs and polyvictimisation that are experienced by a high proportion of autistic individuals (Reuben, Stanzione and Singleton, 2021; Roberts et al., 2015). Each participant was exposed to polyvictimisation by family, friends or partners. Those in positions of hierarchy were amongst the perpetrators and Daisy, Thom and Gwen experienced SAV by their teachers. This renders autistic individuals vulnerable because they put their trust in those closest to them who may be the abusers.

Autistic children and those who have attention deficit hyperactivity disorder (ADHD) are at an increased risk to being violated including polyvictimisation, but it is under-researched (Carlström, 2019). Polyvictimisation is the exposure to multiple forms of victimisation, and researchers and clinicians identify its prevalence (Ford and Delker, 2018). Reuben, Stanzione and Singleton (2021) acknowledge that studies undertaken by other researchers found that the maltreatment of autistic children is considerably higher compared to those who are typically developing, and higher rates of SAV and bullying are reported compared to non-autistic adults.

**I can't tell you - it's my secret**

Elijah, Thom and Gwen never disclosed to their parents about their experiences of SAV:

I didn't disclose to my grandmother because she worries. (Elijah)

As previously mentioned Thom's mum died when he was a teenager.

[Mum] I can't tell her: [Dad] ...said that I was the reason everything in his life had gone wrong: That kinda added to ok, well I won't tell them anything because he already thinks that everything's my fault if something else goes wrong. My parents are pretty much in the dark. (Gwen)

Gwen's dad used her as a scapegoat, and his criticism stayed with her. Possibly, if she disclosed, her dad would blame her for the abuse she endured. The idiom 'in the dark' indicates that Gwen was unable to confide in her parents. She demonstrates her mental resilience:

...I'll deal with it because I had to. I didn't have much choice. My dad obviously wouldn't listen. My mum was too busy dealing with her own stuff. So, I had to either deal with it on my own or break [laugh] break mentally and not be able to handle anything. (Gwen)

Gwen had no emotional support from her parents, and although she accentuated that she could have a mental health crisis, she nervously laughed. Possibly, laughter was her strategy to subconsciously protect herself from her vulnerable position and conflicting emotions.

Daisy and Elsie disclosed to their mother's years after their experiences of SAV. It is worth considering whether they may have disclosed sooner if they had lived in a well-functioning family. Amy disclosed "a year after". "I told CAMHS. I told my parents".

Elsie disclosed to her mum to protect her sister from her step-cousin [Antony] who had inappropriately touched her:

... she wants to invite him to her twenty-first, and I straight away shot that down: ...I said to mum, no don't. I can't I can't have him there and she pried: ... it's Jacob's nephew and I had to tell her, and then I told her and she was angry. So, I didn't tell her about Antony. (Elsie)

Anger is a negative emotion which was felt by Elsie's mum, possibly due to finding it difficult to comprehend the situation.

### **Discussion: I can't tell you - it's my secret**

This subordinate theme elucidated that autistic individuals may not disclose their abuse and is concurrent with the general population. Predominantly, children who have been abused do not disclose it during childhood, and there are limited studies addressing the disclosure rates of SAV within the autism population (London et al., 2005). There are many reasons why survivors do not disclose including shame; confusion regarding knowing and trusting their abuser; abuse is normalised; unsure whether it is abuse; victim-blaming; stigma; self-blame; fearing negative social responses; lack of support; feeling like a burden; not living up to the expectations of family and social norms; and problems regarding gendered responses that may be problematic (Ullman et al., 2020). Survivors voicing SAV often feel punished if they are faced with negative reactions which serves as a silencing function hindering disclosure (Ahrens, 2006).

Although there are challenges to voicing personal experiences of SAV, it may be intensified for autistic survivors as they are frequently silenced. Survivors of SAV may remain silent which is representative of powerlessness (Ahrens, 2006). They may be perceived by some non-autistic people as being of lesser value. Therefore, they may hide behind their secret because they devalue themselves and feel deserving of abuse. This concurs with the experiences of the participants in this research. Additionally, the symptoms of autism may impede disclosure due to barriers in effectively expressing themselves.

### **The ripple effects**

Daisy, Elsie and Gwen had an instilled sense of fear in them as they were acutely aware of the repercussions of their dad's actions if they made a disclosure of SAV:

My step-dad knew something had gone on between me and my boyfriend but he didn't know the severity of it, only because he would go and find him and kill him. My dad still doesn't know. (Daisy)

If anything hits his little girl that's it he loses it [dad] and he *would* actually go and kill someone if he saw me getting shouted at on the street. He'd go and kill em: ...he knew that I dated an older male. He never knew it was me teacher. (Gwen)

...I told my dad when I didn't have exactly a great relationship, he was a distant man. He was always putting his step-children and my half-sister before me and anyone else [sigh]. ...he tracked Jacob down like only a man in the army could and threatened him cus dad has a hunting cross-bow. Although he hasn't got a gun anymore he has a hunting cross-bow, and it's lethal and he threatened Jacob. (Elsie)

There is a synergy between Daisy, Elsie and Gwen as they had previously explained the volatile relationships with their dads. The dichotomy being that when they found out about the SAV, they became protective and took on their fatherly duties. They

each referenced that their dads had the potential to murder. Evidently, they were in a highly emotional state, fused by enraged anger characterised by losing self-control. In Daisy's case, her step-dad and paternal dad were unaware of the details because they would have committed murder, and by concealing it she is protecting them from the ripple effects of SAV.

### **Discussion: The ripple effects**

This subordinate theme highlighted the ripple effects of SAV and its impact on the participants' family. The ripples can affect family members; extend to the workplace; the child's nursery/school or college; and the community (Brown et al., 2019). Ullman et al. (2020) acknowledge the shared challenges faced by survivors in the navigation of family or interpersonal dynamics, and a lack of support impacts on nondisclosure for fear of burdening others. This was the experience of the participants and their family as it affected their mental health. Daisy's mum "took off a week ill, she did not know how to cope". "Nan doesn't know about the abuse... no, it would kill her". Amy said "my dad cried...". Elsie's mum "was devastated" and her mum said "Jacob had raped her as well". The ripple effects of SAV are possibly intensified due to living within a dysfunctional family. The role reversal of caregiving impeded the participants' disclosure due to witnessing the psychological and/or physical pain of their families. They did not want to add to their burden for fear of adding an extra layer of oppression onto their troubled family. This defies the myth that autistic people are unempathetic.

Recognising that support is unavailable and/or that disclosing SAV may be disturbing for other people could be the equivalent to survivors who experience negative reactions to disclosure and subsequently, unfriended (Ullman, et al., 2020). Negative

responses can silence a survivor (Ahrens, 2006). A lack of perceived support can determine a survivor’s nondisclosure because of the fear of being blamed, disbelieved and rejection, particularly by their family (Ullman et al., 2020).

### 3. Autistic chameleon in a crowd

4.5 Table 3: Superordinate theme and related subordinate themes

Subordinate theme	Daisy	Elijah	Thom	Gwen	Amy	Elsie
Identity issues: Who am I?	✓	✓	✓	✓	✓	✓
People-pleaser	✓	✓	✓	✓	✓	✓
Underneath the mask was the abuse		✓	✓	✓	✓	✓
But was it abuse? I never said no			✓			✓

#### Identity issues: Who am I?

Each participant had various diagnoses and co-morbidities in addition to their autism diagnosis, and they had similar mental health problems. Daisy acknowledged that she had PTSD. Evidently, the other participants had PTSD but they possibly did not recognise it as it was not discussed.

Five participants felt the emotion of anxiety which was severe and characterised by their psychological and physiological feelings, and demonstrated below:

...I was having fits with the pressure and the stress. It got diagnosed as non-epileptic disorder. I went into a depressive state: ...bad mental health space... PTSD. (Daisy)

Depression. Anxiety disorder. Bi-polar disorder. Schizophrenia.  
Oppositional defiant disorder. Intermittent explosive disorder.  
(Thom)

Thom's synopsis highlights his possible misdiagnoses. In the 20<sup>th</sup> century children were frequently diagnosed as schizophrenic when it was possibly autism, and this was probably Thom's experience.

...depression and anxiety: ...episodes of psychosis: ...struggled with my weight from about twelve until eighteen nineteen.  
(Gwen)

...borderline personality disorder, depression, anxiety, OCD, and dyspraxia. (Amy)

...I've got borderline personality disorder: ...anxiety: I was on sertraline: ...mental health condition. (Elsie)

Elsie was medicated with sertraline; a type of antidepressant indicating that she may have experienced depression, panic attacks and/or PTSD. Each participant had a late diagnosis of autism which detrimentally impacted upon their identity and mental health.

If I got diagnosed when I was five like most people would've done, I think all of this would've been a totally different way of handling me..... (Daisy)

Daisy assumed that five was the average age to receive an autism diagnosis. She reflected on the supposition that if she had been diagnosed in childhood, she would have been treated differently. Understanding how autism affects the behaviour of each autistic individual is conducive to how they are treated by others.

I was at a Church of England school and females didn't have autism. It didn't exist. It was a naughty boy syndrome, and when

I got diagnosed and told my dad he went but you're not a naughty boy. He couldn't understand it because I wasn't male. (Daisy)

The ethos at Daisy's school did not recognise that females could be autistic; therefore, any symptoms associated to autism may be unnoticed. During the era of Daisy's education, there was unawareness of autistic females in comparison to males. Currently, educators may play a role in identifying the signs of autism in an individual and subsequently, signposted for a diagnostic assessment. Although Daisy was diagnosed in adulthood, her value seems to have been undermined. Her dad was unable to comprehend it because he associated autism with naughty boys which is derogatory towards autistic individuals. He was unaware that girls can also be autistic and Daisy did not fit the mould. This is unsurprising because historically it was perceived that autism predominantly affected males (Whitlock et al., 2020). The lack of awareness of female autism by Daisy's educators and her family inevitably impeded her receiving appropriate support.

[Diagnosed autistic] ...officially 2011. ...other psychiatrist's, educational specialists were saying I've got ADHD. I've got autism. I've got this condition, but nothing was formally written until I needed support at the university: I got a full diagnosis. (Elijah)

Evidently, Elijah was a victim of differential diagnosis and/or diagnostic overshadowing. He experienced difficulties during his schooling through to university as he sought help from various professionals on his route of diagnosis. The diagnostic process was unstraightforward as he referred to different diagnoses. He received an autism diagnosis in adulthood and he possibly struggled due to late diagnosis as he recognised his need for support.

At the time of abuse Thom did not have an autism diagnosis and he commented “no, no that came much later”. Thom also had six various diagnoses and he received an autism diagnosis in mid-adulthood. Possibly, differential diagnosis and diagnostic overshadowing negatively impacted upon his identity. He commented “I struggle from an autistic perspective to know who I am”. Similarly, Gwen struggled as she had a late diagnosis:

I struggled with life anyway. I didn't really know why like obviously having my late diagnosis of autism. I didn't know that life wasn't the same for everyone. I didn't know that people didn't struggle with emotional cues like face recognition of emotion. I didn't know that people didn't struggle with that. I just thought I was really behind and I was panicking because everyone else was just breezing through life... maybe they are all being abused behind the scenes. Surely, they've all got relationships and they're all just fine when really, they weren't. (Gwen)

Evidently, Gwen's life was fraught with confusion. Not having an autism diagnosis contributed to the way she perceived herself compared to others. Upon diagnosis she had more understanding of why she struggled. This is demonstrated as she localised some of her symptoms of autism. Possibly, this may have been associated with wanting to be like a non-autistic person. She reflected and her figurative use of language suggests that everyone around her is successful, and she could not understand why, if they too were being abused.

[Autism diagnosis] ...sent me downhill. It made me feel like I was not normal: It answered a lot of questions but I still feel there's a lot of stereotypes, and because of having autism you're seen differently. (Amy)

Amy's reference to 'downhill' demonstrates deterioration whilst in receipt of her diagnosis because she did not feel 'normal'. Possibly, her meaning of normal is associated with non-autistic people because she refers to the stereotypical views of

autistic individuals and the stigma attached to them. Amy had many questions that she wanted answering suggesting that she was confused, but her autism diagnosis was beneficial to an extent because it gave her answers. She commented:

[Autism diagnosis] ...it was in a sense that relief. I didn't even know what was going on at the time because I was going through a mental breakdown. (Amy)

Similarly, Elsie and Amy were confused regarding their emotions and BPD and in Elsie's case, autism:

Autism, emotions, how does that... I don't know... I'm I'm still learning the whole, trying to get used to the idea of them being separate. That one is an illness and one is the way of who I am because I've been told so much that the BPD is everything. That that is the root of my cause and all of my problems, sorry, and layers of symptoms and everything that I, say is because of BPD. (Elsie)

Elsie paused twice as she reflected upon the correlation between autism and emotions. She was confused about her identity which is understandable considering that she was defined by BPD. She tried to separate autism and BPD and process how emotions are correlated with them. 'Layers of symptoms' suggests that her authentic self is made up of many components. Elsie did not have an autism diagnosis until adulthood but it seems that she has started to identify as autistic as opposed to BPD. This would have been confusing, particularly as she had been told things that did not reflect her experience or adequately describe her, possibly due to trying to fit into her labels.

Similarly, Amy was defined by BPD:

I want to feel some kind of emotion but with my BPD, I either feel emotions or I don't feel nothing at all. (Amy)

Interestingly, Amy refers to BPD and not autism when she commented on wanting to feel some form of emotion. Amy and Elsie felt confused about their diagnosis of BPD and emotions because BPD affects an individual's ability to manage their emotions. Similarly, autistic individuals may experience difficulties understanding and recognising emotions and effectively expressing them (Molnar-Szakacs et al., 2009).

### **Discussion: Identity issues: Who am I?**

This subordinate theme draws out the effects that a late autism diagnosis can have on an individual's identity. It supports the grey literature whereby the bloggers had an identity crisis due to having a diagnosis in adulthood and the stigma associated to it. Labels can have negative connotations regarding the way an individual identifies with themselves and how they are perceived by others. This is due to incorrect assumptions made by people as they use labels to define them, failing to see the person beyond their diagnosis. Stigma is deep rooted within society's negative views of individual or group characteristics or identities, and there are health impacts generating a range of vulnerabilities and risks (Turan et al., 2019). Cook and Décary (2020) acknowledge the importance of studying diagnosis beyond normal metrics, and to improve the outcomes for individuals they recommend research into linking phenotyping and prognosis evidence.

This theme illuminated the complexities concerning the multiple identities of each participant and the implications it had for their mental health. This is because of the numerous intersects associated with stigma including disability; SAV; mental health; dysfunctional family environment; gender; sexuality; late diagnosis; differential diagnosis; diagnostic overshadowing; oppression; marginalisation; masking; and/or

people-pleasing. Mental health does not exist independently of individuals multiple identities, and the stigma and intersect between them may add to their layers of oppression. Intersectional stigma intensified the oppression that each participant experienced, and this research highlights their resilience as they endured multiple intersects of abuse. Their fight for survival was profound and there is a dichotomy in that to keep themselves safe, they put themselves in danger.

Identity is fundamental because it gives a sense of belonging which is essential for well-being and confidence “Simply put - your identity is ‘who you are’” (The Children’s Society, 2023, no pagination). Some of the participants in this research attempted to separate their diagnoses and perceived autism as an appendage adding to their unauthenticity. The bloggers and the participants either struggled to understand their identity, or felt a loss of identity due to the intersect of different diagnoses and comorbidities. Cook and Décary (2020) recognise the complexity concerning the basic understanding of diagnoses and that it is an iterative and necessary process, and having just one diagnosis may consist of multiple phenotypes. Each participant was affected by diagnostic overshadowing and/or differential diagnosis. Diagnostic overshadowing can inhibit appropriate treatment for people’s mental health (Shefer et al., 2014). Differential diagnosis is worth consideration as it distinguishes between more than two illnesses with comparable symptoms. Cook and Décary (2020) state:

Differential diagnosis is a systematic process used to identify the proper diagnosis from a set of possible competing diagnoses. (p. 2)

The language used to describe autism contributes towards autistic individuals being treated harshly (Woods, 2017). Medical terms describing them including deficit or disorder may be deemed offensive (Milton, 2017; Woods, 2017). Each participant in this study perceived themselves to be of lesser importance than non-autistic people. This may be compounded by diagnostics as Milton (2017) identifies that to get an autism diagnosis, the clinician perceives the client as dysfunctional regarding the symptoms of autism. To be identified as a deficit, disordered and/or dysfunctional could influence a person's decision to go through the diagnostic process. Non-autistic people judge autistic people cruelly, and this unconscious bias is in all parts of society for anyone who behaves atypically to the standards of non-autistic individuals (Belcher, 2022).

This research highlighted the intersect between identity and psychological well-being which is vital regarding the safety needs of autistic individuals. The intersection of marginalised identities is an important factor in accounting for suicide-related mental health disparities (Cramer et al., 2020). This was the experience for Daisy, Gwen, Amy and Elsie as they attempted to take their own life. The lack of an earlier autism diagnosis negatively impacted upon their mental health. Consideration given to whether the participants would have experienced a better outcome if they had a diagnosis in childhood is important. Arguably, if they had understood their symptoms of autism, they may have been less sexually vulnerable, and either minimised or prevented experiencing SAV.

### **People-pleaser**

Each participant people-pleased:

I don't know whether it's the autistic, the autism, or whether it's just me. I thought about them [other people] first before it became about my own safety... I'd rather everything be ok for everyone else than for me cus then life's easier to deal with... (Daisy)

Daisy tried to separate herself from 'the autism' in the same way that Elsie struggled to separate her diagnoses. Daisy's use of language suggests that she perceived autism as a unit of its own and separate from her identity. She reflected upon her personal safety, and demonstrates selflessness. Whilst being selfless is deemed a good trait, it can have negative repercussions whereby an individual can be taken advantage of. In the midst of her confusion, she lost sight of who she is which is also associated with selflessness.

...Victim Support was at the university giving their flyers out. I took some of the *material*: [Grandmother] ...she found it and she was really worried something happened to me. I don't want to worry her even more than say I got raped. (Elijah)

Elijah demonstrated people-pleasing by protecting his grandmother from the pain of his rape. He emphasised 'material' signifying its content as it provided advice and support for victims of abuse. Although his grandmother addressed her suspicions that he was a victim, Elijah denied it to shield her from the truth.

I want people to be happy. I don't know how to make them happy so I'm reliant on them to tell me what makes them happy, and whatever it is I'll try and do it: I've always been like that... (Thom)

There is a dichotomy in Thom's excerpt as he repeated 'happy' symbolising his need to make others happy. It seems that he had not experienced the emotion of happiness characterised by positive emotions and commented:

I don't know what the rules are so if somebody when I'm eight years old wants me to suck their cock, then I'm going to suck their cock, because that's what they want me to do. That must be alright because that's what they want me to do, and if it wasn't alright they wouldn't want me to do it, so I'll do it... It's not quite the same as saying I didn't know any better. It wouldn't matter whether I knew better or not. That's what they wanted me to do and I wanted to make them happy and it is an overwhelming compulsion. (Thom)

Thom felt compelled to make people happy and as an adept people-pleaser he had no limits, particularly as he did not understand social rules. There are two important factors to be considered. Firstly, it is possible that he wanted to make other people happy because seemingly, he had not experienced a happy childhood. Secondly, his language exemplifies his literalism as he did what the abusers asked of him. This is demonstrated by his repetitiveness of 'that's what they wanted me to do'. He was under the illusion that the abusers believed that their actions were acceptable, because otherwise they would not have asked him, thus highlighting the implications regarding trust.

Somebody wanted some money. So, I gave them money which I couldn't afford and it left me unable to pay the bills for a month, two months actually. I couldn't not do it cus that's what they wanted. That made them happy..... Logically at forty-six I know that was a stupid thing to do but I couldn't not do it. (Thom)

Thom's compulsion to making people happy led to his financial abuse. He reflected in silence, and he made sense of his actions.

At thirteen I was regularly having sex with two women; one in her forties. ...she was late forties or early fifties. The other late thirties and we would go to their houses and it would be a physical thing, whatever they wanted to do. (Thom)

Thom was not perturbed by his sexual encounters with much older women, and his language seemed nonchalant as he referred to physically pleasing them. Furthermore:

...being introduced to the idea [not to people-please by someone he respected] and being made to do it, and made to carry it out, an analysis of every decision I made and to literally say why am I doing this? Who is it pleasing? Because the person I need to be pleasing is me. I've got to learn what pleases me. I don't know. So, I've got to learn all of that stuff and that's the autistic side that's the... erm... because I'm so focused on making everyone else happy, I've never thought about what makes me happy and now I'm starting to. Now I'm making myself do it. It's not easy. It's not a necessarily pleasant process because the minute I try and do it I go no it's selfish. No, I can't do that. I have to stop myself saying that and then have to try again and so it's not easy to do. It's not straightforward. (Thom)

The person who introduced Thom to the concept of not people-pleasing ensured that he worked on himself to discover what pleased him compared to pleasing others, and evidenced by his repetition of 'made to'. Although generally people intuitively know what makes them happy, this was not Thom's experience and it was a complex process because he had no concept of what made him happy. Thom referred to the 'autistic side' suggesting that he perceives autism as a separate entity, and possibility that autistic people are typically people-pleasers. Evidently, he started peeling away his people-pleasing mask because he had to make himself go through the difficult and unpleasant 'process'. His belief that he was 'selfish' indicates how people-pleasing was deep-rooted because he felt that he was lacking consideration for others as he had to now think about his own happiness.

**Reflective box**

I visualised Thom's home environment whereby his mum was terminally ill and the fractious relationship he had with his dad. I felt sadness that he was not cared for and protected whilst developing as a child. As a mother, Thom's experience provoked a mixture of emotions in me and the concept of an eight-year-old boy performing oral sex was repulsive. As he told me his story, my blood boiled as I felt

loathing towards his abusers. I was frustrated that he had not been raised in a family that could teach him boundaries and protect him. I felt sorrow for Thom as he had missed out on his childhood. He was surrounded by adults who took advantage of his vulnerability. It seems that Thom was seeking some form of attention that had been missing within his childhood. This made me think about the stable environment my children had growing up, and the love and support they had. The impact of living within a dysfunctional or well-functioning family is profound, particularly as the experiences of children frequently influence their decisions in adulthood either positively or negatively.

[Other people] ...you have enough to deal with: ...I don't want to add to that: I'm good at caring for people but I'm not good at caring for myself. (Gwen)

Gwen's language typifies her as a people-pleaser as she acknowledged that she is willing to put other people's feelings before her own. She cares for others but she has poor self-care, which is possibly linked to her self-esteem and/or self-respect as she does not feel worthy of self-compassion.

Amy too typified as a people-pleaser:

He made me sign a contract over the internet to say that I consent to him dominating me in the bedroom. It made me feel so horrible because I went ahead and did it. I went ok, if this is what you want then I will give you what you want. (Amy)

Amy repeated 'made me' indicating that she felt compelled to please her boyfriend and put his needs over hers. She has conflicting emotions and her actions do not correlate with her feelings. 'Horrible' is a negative emotion, and her emphasis on 'so' symbolises the extent of how he made her feel. Her language seemed nonchalant, possibly due to knowing that she had no control other than to please.

Elsie acknowledged "I'm a people-pleaser, well and truly..." because of her desire to be liked:

...I didn't really have friends: ...I was really really trying to be liked: ... I would do anything for them: I even back then still made everyone happy. I would sacrifice my own needs, my own happiness for my sister, for my mum, even for Jacob because that was our family and it was up to me to keep us going to keep us strong. (Elsie)

Elsie repeated 'really' demonstrating the depth of longing for approval. Similar to Thom, she had no limits and 'sacrifice' signifies that she is willing to surrender everything to please her family.

[Step-cousin] ...he was convincing me that it's ok [touching each other's genitals]. We are not cousins and you are very beautiful and it's ok. I struggled with the idea of saying *no* because this is what he wants isn't it erm, I just have to make him happy, but yet it's not making me happy, but yeh it was it was horrible. (Elsie)

Elsie referred to feeling 'horrible' in the same way as Amy. They were both in situations whereby they did not want to do something but they put the abuser's feelings above their own. Elsie evoked emotional responses as she referred to 'happy' and 'horrible' in the same sentence. Her internalised feelings were conflicted because although she wanted to make her step-cousin happy, it did not make her feel good. Despite his compliments, Elsie emphasised 'no' and she had difficulties in saying it because of her desire to please him.

### **Discussion: People-pleaser**

This subordinate theme revealed that each participant was a people-pleaser, and supports the grey literature as people-pleasing was a common theme with the bloggers. It exposed the extremities that autistic individuals endured to fit in and be accepted within society, but all too often they are rejected. Non-autistic people may misperceive autistic individuals which acts as a barrier to social integration and

acceptance into a predominantly non-autistic society (Alkhaldi et al., 2021). Social difficulties may arise from the perceptions, judgements and social decisions made by those around autistic people (Sasson et al., 2017).

Although there is an ample supply of grey literature addressing the effects of people-pleasing, there is limited academic literature. This is surprising considering that it can detrimentally impact the psychological and physiological health of a people-pleaser. There is a correlation between self-acceptance and people-pleasers, and if an individual has low self-acceptance, it intensifies people-pleasing and vice versa (Devina and Murdiana, 2024). People-pleasing is exhibited in various ways including fear of rejection; unable to say no; inability to escape unhealthy relationships; inconsiderate to one's own needs; taking responsibility for others; care-giving; co-dependency; and being overly apologetic. Habitually, people-pleasers sacrifice themselves for the sake of others (Seltzer, 2008) which was Elsie's experience. Non-autistic people can also be people-pleasers but the effects may be heightened for autistic individuals. Their intense desire to be accepted often supersedes their own safety requirements and makes them easy targets for perpetrators. SAV impacts upon the social inequalities of wide-ranging cases and contexts (Armstrong, Gleckman-Knut and Johnson, 2018). Woods (2017) states that autistic individuals are forced by a predominant neurotype society to adapt to an environment that is not adjusted for them. Consequently, people-pleasers can be perceived as chameleons in their attempt to camouflage themselves to fit in with people around them (Seltzer, 2008).

### **Underneath the mask was the abuse**

Five participants were maskers to the depth that they concealed their abuse. The damage caused by adept masking detrimentally impacted upon their authenticity and identity.

...I don't have to hide it [rape]: ...that really was bottled up [rape]. I went to get professional help about it after my friend committed suicide. (Elijah)

Elijah did not refer to himself as a masker but his use of language suggests otherwise as he referred to 'hide' and 'bottled up', exemplifying that he had masked and concealed his SAV.

The following excerpt contradicts Thom's previous comments whilst referencing not being affected by abuse, but here he refers to how it impacted on his identity:

Through the therapy, the various therapies I had found that I could talk about what had happened. I could talk about how it had affected me but I couldn't talk about me... because I didn't know about me. I didn't know who I was if that makes any sort of sense. It's a bit weird. It felt very weird. It felt like all I had was the masks and characters and there wasn't a me underneath. It was just masks all the way down. I think that's the real damage that the abuse had caused. (Thom)

Thom was able to talk about his experiences of abuse and how it affected him but he was unable to talk about himself. He repeated 'I didn't know' signifying that he has no sense of his authentic self. The abuse possibly took away his identity together with not receiving an autism diagnosis until mid-adulthood. Thom repeated 'weird' indicating that it felt strange, and that it was unusual to emotionally and/or physically feel that way. He characterised himself as imagined figures 'masks and characters'. Thom is not in touch with himself, and he has difficulties in emotionally connecting in

relationships. He realised the depth of his emotional 'damage' as he retracted the word 'bit' to 'very' regarding 'weird'. Thom articulately demonstrated the damage caused through masking and playing characters whereby he lost his authentic identity:

The fact that essentially there was no me, it was as if I had died and all of the rest all of the masks and characters were all that were left: It's like when an actor dies, the actor is gone. All their films are still there and you think you can understand the actor by watching their films but you can't. You're just seeing characters so anyone who's talking to me, and thought they were to getting to know me wasn't because there was no me. There was just whatever character I was portraying that day and it was as if I had had died erm, actually that's the first time I've ever thought about it like that, but that makes a lot of sense..... [sobbing]. (Thom)

As Thom narrated his experience there was a palpable sense of emptiness reflecting how he felt as he repeated 'there was no me' and 'it was as if I had died'. Thom's reality was that he had no existence apart from the disguises. This is demonstrated by his comparison to when an actor dies and no longer exists, but their films are still there as if the actors are existing through them. Just as actors do not reflect their authentic self, Thom felt that anyone who thought they were getting to know him were not. It was an untrue reflection, and all they got was an insight into the character he was depicting on that day. Possibly, Thom's association to cinematography is a form of escapism which can be related to existing as opposed to living. He possibly perceived himself as public entertainment and not the person at the centre of abuse. The effects of abuse impacted upon his self-perception and he was unable to identify with himself because he had masked for so long that he did not develop a sense of self or identity. I allowed him silence which was poignant as it exemplifies the double hermeneutic process, 'that's the first time I've ever thought about it like that'. The silence was broken as he

sobbed at the realisation that he had effectively processed his feelings and possibly felt relieved.

...I'd put on this great face: It feels like its been like that my entire life. Its been like oh no I'm really happy, I'm bubbly, I'm smiley, I'll make all the jokes. I make a lot of self-depreciating jokes [laugh]. I'll laugh through this stuff because it doesn't bother me anymore, but when people pull me up on that and they're like aw that's not a very good thing to joke about I'm like, no don't make this a reality because when it turns into my reality I go crazy, and that's when I have to start to go into hospital and things again. (Gwen)

Gwen had masked her entire life and put on a good façade. Her language symbolises that on the outside she wanted to appear jovial; however, her emotions are conflicting with embodied experiences. Possibly, her reference to 'self-depreciating jokes' was mistakenly used and self-deprecating corresponds with her dark sense of humour. She is aloof whilst talking about her SAV, but she adeptly masked the true extent of how grim it was. She had made it fictional because when people addressed the way she joked about her life, it became her 'reality' which made her feel insane. She would go through the repeated process of hospitalisation suggesting that her exterior façade runs counter to her innermost feelings.

Amy masked the trauma of her miscarriage:

...I felt like a really bad pain in my stomach: I saw a spot of blood in my clothes and the pain got worse. This is how I'm trying to describe it because I'm not very good at describing what I've gone through because I can't open up to people. I saw a spot of blood in my clothes and I broke down because I was in so much pain, and all of a sudden there there there was like tissue in the toilet and I panicked. I just didn't know what to do. I just didn't know who to turn to. I just didn't know. My mum and dad was unaware of this, and everything that happened came crashing back in my head and I just broke down... (Amy)

Amy expressed herself effectively as she detailed her miscarriage despite feeling inarticulate. She was unable to openly talk about her experiences of SAV before her interview. This may be related to feeling emotionally removed from people, trust issues, shame, guilt, vulnerability, and/or fear of resurfacing trauma. Amy 'panicked' indicating that she was thrown into a state of fear at the realisation of losing her baby and she felt helpless. She repeated 'broke down' suggesting that she felt intense physical and emotional distress due to the sight of her miscarriage. Amy reflected and evidently, she had a flashback. She concealed her trauma from her parents "I just hid away, in my bedroom".

In emotion work, researchers may witness someone who is psychologically distressed and crying uncontrollably, compelling researchers to reflect upon aspects of their own experiences (Dickson-Swift et al., 2009). Likewise, the above excerpt resurfaced painful memories for myself. Within sensitive research, researchers may give an outward bodily display conflicting their true feelings (Dickson-Swift et al., 2009).

**Reflective box**

Amy's description of her miscarriage touched me. It brought out my maternal instincts and just as she felt helpless, I felt it too. She highlighted the aftermath of rape and its long-term psychological effects. Several years on from her experience she was able to vividly describe her miscarriage. She was shaking uncontrollably as she recalled her painful memories. Her whole experience was wriggled with trauma and emotion starting from conceiving the rapist's baby, to accepting motherhood, to miscarriage. She was grief stricken. She was robbed of her virginity and she lost her baby. I was unable to console her and I felt her loss. She was unable to think clearly as three times in succession she said 'I just didn't know'. My painful memories resurfaced as my youngest daughter miscarried a baby whilst in an abusive relationship; she bathed in her own blood and the remnants of her miscarriage. I emphasised deeply with Amy as I felt helpless whilst being unable to console my daughter.

I don't want to ask about how your day did. How you went to school. I I don't care [laugh] you know. It's just too boring, but yeah you have to pretend because that's how people are. You're supposed to ask how a person's day is even if you don't want to know. (Elsie)

Elsie learnt the social conventions of polite conversation in social situations, but she disregarded small talk. She gave a false representation of herself as she was an adept masker and disguised her authenticity and the symptoms associated to autism to appear non-autistic.

### **Discussion: Underneath the mask was the abuse**

This subordinate theme revealed the dangers of masking. To stay safe autistic individuals may mask parts of themselves but it can result in exhaustion (Pearson, Rose and Rees, 2023). It is mentally and physically exhausting and it can intensify anxiety and depression (Belcher, 2022). Camouflaging is not specific to autistic people (Fombonne, 2020) and non-autistic individuals may also mask. However, autistic people may become more adept maskers due to their desire to gain social acceptance and to disguise being autistic; therefore, it can be deep-rooted and detrimental to their health and well-being (Belcher, 2022; Hull et al., 2017). Autistic maskers tend to mask on a daily basis and they may experience devastating life-long repercussions. It can intensify suicidal behaviour (Cassidy et al., 2018) concurring with these research findings.

The participants in this research desired to be accepted which made them vulnerable and positioned them susceptible to SAV. Masking is a strategy of unconscious awareness that individuals develop to form connections (Belcher, 2022). The

participants in this research were socially challenged as they endeavoured to be accepted, and they adeptly masked their authentic self. They engaged in risky behaviours as they appeased the needs of others. Masking and people-pleasing impeded their judgement in understanding the intentions of their abusers. It impacted upon their identity and intensified their sexual vulnerability. This research highlighted that those challenges are a fundamental factor as to why the autism population is highly prevalent to SAV compared to non-autistic people.

Belcher (2022) who is autistic was diagnosed aged twenty-three and as she became knowledgeable about masking, she was able to understand that she had disguised her autistic traits. This was possibly the case for the participants in this research as they inadvertently disguised their individualities as they did not receive an autism diagnosis until adulthood. Belcher (2022) frequently battles autistic 'burn out' and sometimes she has a mental health crisis because of trying to fit into a world that is not adjusted to her thinking style. She felt pressurised to conform and it impacted upon her time and energy because she was rarely able to do what she desired, and was unable to be her authentic self. She realised that she had no idea of who she was or what she liked (Belcher, 2022). Her experiences are similar to Thom's "there was no me". In both cases, they actively emotionally suppressed uncomfortable thoughts and feelings and presented those that are perceived to be the most acceptable.

Autistic individuals can feel a sense of belonging whilst being with other autistic people and family; hence, they can be their authentic self and engage with happy social interactions (Crompton et al., 2020). If autistic people removed their mask whilst interacting with other autistic individuals, they may have the opportunity to be their

authentic self, and reduce the risk of SAV by not people-pleasing to be socially accepted.

### **But was it abuse? I never said no**

Thom and Elsie felt confused regarding whether they had experienced SAV. There is a recurring theme throughout Thom's narrative as he questioned it:

I didn't have the first clue about erm relationships, and my perception of them was that I had no control, no say in what happened within a relationship: I was just there to facilitate whatever, whoever I was with happened to want at that time, and I think that's very much a product of the abuse: ...relationships in quotation marks, at university at that that age were not healthy. Erm whether they could be categorised as abuse in the same way, I'm not sure. (Thom)

Thom was unable to recognise that reciprocation was involved in relationships, and he was the one who gave himself to others but there was no mutual exchange of reciprocity. His language symbolises that he has no right to express his opinion, and that his feelings are unimportant. Thom's vocabulary is interesting 'a product of the abuse' signifying that he was a physically damaged commodity because of being taken advantage of. Thom contradicted himself as he recognised his relationships at university were unhealthy, but then he was unsure if they could be classified as abuse. He struggled with the idea that he never said, no:

I struggle with even thinking of the stuff when I was eight as abuse because I never said *no*: I never made any attempt to stop it happening. So, I'm not even sure that was abuse: I don't see how... a thirty-year-old man cannot stop something they don't want to happen. So, there must be a part of me that wants it to happen. So, is that abuse or not? (Thom)

Thom questioned whether it was abuse because he repeated 'never' and emphasised 'no' suggesting that he did not do anything to prevent it. This may link with research on CSA from non-autistic survivors, and possibly a common phenomenon where people are coerced without violence. Thom reflected, and even as a mature adult he questioned whether it was abuse and he commented:

I'm into teenage years. Erm I'm not even clear if it was abuse or not. I just don't know [sigh]. [Aged thirteen] I was surrounded by women owning horses mostly in their late thirty's, early forties. Erm and if they expressed any interest then I would be more than happy to let them do whatever they wanted pretty much. I'm not even sure that that would be classed as abuse. (Thom)

Thom did not particularly recognise that he had experienced CSA but undoubtedly, he had. He sighed and, in this instance, it could be related to negative emotions such as confusion, anxiety and/or sadness.

I've gone to swinger's parties. I've done group sex because someone I was with wanted me to. Don't like it. Don't enjoy it. Is that abuse? I did it willingly. It was consensual, but I didn't want to. I don't know if that's abuse or not so I would guess some people would say yes, I've been in abusive relationships. I don't know. I genuinely don't know... (Thom)

As a forty-six-year-old man Thom is still trying to understand abuse. His confusion stems from his willingness to engage in behaviours that he did not particularly want to do. There is a synergy between Thom and Elsie's cognitive processing regarding making sense of whether they had experienced SAV:

If I wanted to stop someone, I could've done. I'm physically big enough and strong enough. I'm playing rugby against adults... So, to the extent that that part of this is why I question whether it was abuse cus I could've stopped it couldn't I? If I'd wanted to, so obviously I didn't want to. (Thom)

It feels that Thom is convincing himself that he could have stopped the abuse. He referred to his physicality believing that men who are strong can stop it, and he concluded that he must have wanted it to happen.

I couldn't understand why I couldn't stop this: I couldn't physically fight him off. I couldn't physically fight him off does that mean I was consenting to him doing that, it's confusing really: ...didn't move, didn't do anything: I didn't say anything, didn't do anything. That means it was ok. That means I gave consent, but I didn't want it to happen... (Elsie)

Elsie repeated 'I couldn't physically fight him off' and this confused her because she questions whether she had consented but evidently, she froze. Confusion is an emotion defined by one's thought process, and Elsie is trying to work through her experience. It is interesting that she feels confused as she referred to 'couldn't' three times regarding either understanding or stopping her experiences. Subconsciously, she is aware that she was non-consensual but she is trying to justify why she did not stop it. She repeated 'didn't' signifying feeling guilty. Guilt is a self-conscious emotion, and Elsie reflects upon her behaviour and perceives herself as the culprit because there is no reflection on the actions of her abusers.

### **Discussion: But was it abuse? I never said no**

This subordinate theme exposed the complexities of recognising the signs of SAV which is important for victims with the inability to communicate their needs. Consideration deserves to be given to those who may not recognise that they have been abused and the implications it has for disclosure. Autistic individuals may display signs of anxiety, stress or mental health which may not trigger the usual safeguarding

concerns. SAV often goes unnoticed as it is frequently misattributed to the symptoms of autism (Edelson, 2010). Thom and Elsie were confused regarding their experiences of SAV because of their inability to say no and/or their attempts to stop it. It is important to consider the implications associated with tonic immobility. It is a common reaction to threatening stimuli which is a freeze response and comprises physical immobility; muscular rigidity; inability to speak; and/or numbness whilst mentally conscious (Schiewe, 2019). An individual may not have the ability to remove themselves from danger and subsequently, freeze (Kozłowska et al., 2015; Schiewe, 2019). This was Elsie’s experience as she physically and verbally froze whilst being raped, and questioned if she had been consensual. Tonic immobility does not signify that a victim is consenting. However, it heightens confusion because some individuals deem that a lack of resistance means that they have consented and consequently, they may be disbelieved. Additionally, if a survivor experiences a negative response from family and friends, it reinforces their uncertainty about if it qualifies as rape (Ahrens, 2006).

#### 4. Rape culture: The reality beyond the myth

**4.6 Table 4: Superordinate theme and related subordinate themes**

<b>Subordinate theme</b>	<b>Daisy</b>	<b>Elijah</b>	<b>Thom</b>	<b>Gwen</b>	<b>Amy</b>	<b>Elsie</b>
Sshhh! Taboo of a male being raped		✓	✓			
Loss of empowerment and control	✓	✓	✓	✓	✓	✓
Sexual objectification	✓	✓	✓	✓	✓	✓
Blurred lines: This is normal - Isn't it?	✓		✓	✓		✓
Victim-blaming	✓	✓	✓	✓	✓	✓

## **Sshhh! Taboo of a male being raped**

The taboo of a male being raped is demonstrated by Elijah and Thom impacting upon their disclosure decisions:

In society men are quite dominant and can defend themselves. I don't feel like I can match with what society perceives as masculine, and what a man should be which is partially why I kind've not disclosed to anyone that I've been raped. I just feel as though I wouldn't be taken seriously: The society we live in today has this toxic masculinity image of a man having a six pack, having a wife, children, being the bread-winner of the home: I think if a man was raped, society would look quite down on that person because it doesn't meet, it doesn't match with societies expectation of a man: You hear a lot about women being raped and abused but... it just feels awkward to say it happened to me. (Elijah)

Elijah does not identify with the toxicity of the images associated with masculinity. As a gay man, he feels that he is unable to fit into society's perception of masculinity. He makes a general statement regarding SAV against women. He reflected upon his belief that it is more widespread in women compared to men, and he is embarrassed to admit that he is a male survivor. This is possibly due to being drawn into society's stereotypical perception that men are able to protect themselves, impacting upon his willingness to disclose. When he did disclose he said "wasn't laughed at, er you know I got respect" running counter to his initial beliefs.

At thirteen I was pretty much six-foot-tall, seventeen stone, playing rugby, riding horses. Erm that's not the sort of person who gets abused. (Thom).

Conversely, Thom's bodily image fits into Elijah's belief of society's ideal view of masculinity. Thom described himself as the mien of a physically fit and masculine looking man. It is a reminder that autistic individuals are other types of people too:

strong, sporty, and/or attractive. Some of these other traits mask vulnerability creating confusion. It seems that Thom got an unhelpful reaction not because of autism but because of those positive traits. Thom exemplifies how masculine and powerful men can fall prey to SAV. Similar to Elijah's belief that he would be laughed at for disclosing SAV, Thom revealed:

...I went to a teacher. That was as good as it got and I was essentially laughed at so it kinda put me off. It was dismissed. It was just don't be silly. No. You've made that up. (Thom)

Thom had trust issues with those in positions of power. They had perpetrated him and subsequently, disregarded his attempt to disclose SAV as it was insinuated that he had fabricated his story. This negatively impacted upon future disclosures:

You go the police and say I was a thirteen-year-old lad surrounded by girls and some of them fucked me, and they'll go oh weren't you lucky. They are not gonna go *were you raped*, are they? The reaction I get from men when I say that at thirteen fourteen I was regularly fucking thirty forty-year-old women with nice cars, and then went on to be an escort, they go shit. Wished that happened to me. Wish I had. Yeah. No, perhaps not... (Thom)

Thom believed that young men fantasise about having sex with older women. This factored into his non-disclosure because he thought the response would be that it was a blessing. He sarcastically emphasised that the police would not say 'were you raped' meaning they would ridicule him. He explained:

One of the reasons why I wouldn't go to the police is because I'm a bloke. Blokes don't get abused, blokes are abusers. Blokes don't get raped, blokes are rapists. I'm not going to get taken seriously. Six-foot, seventeen stone, ex rugby player, looks like a biker. I'm not going to get taken seriously by the police, am I? [laugh]. (Thom)

Thom's awareness of society's perception that men are abusers contributed to his non-disclosure. He thought that it was laughable to report SAV because of his masculinity. There is a hint of sarcasm in his voice which could be a sign of veiled anger. Thom used the same words as Elijah regarding whether he would be 'taken seriously'.

There's still a stigma to about a bloke being abused particularly about a bloke being abused by women: There's still a stigma attached to autism and mental health and everything else. The world is full of stigmas. (Thom)

Thom repeated 'stigma' indicating that in present-day there are negative social beliefs concerning unfair viewpoints towards individuals. Possibly, he had experienced many stigmatising attitudes regarding his characteristics related to autism; marginalisation; an abused man perpetrated by both genders; and mental health.

Elijah commented on the media giving attention to male-on-male rape:

There tends to be more awareness of male rape that's starting to become a bit louder than it was four five years ago. In Coronation Street there was a storyline of male rape. (Elijah)

### **Discussion - Sshhh! Taboo of a male being raped**

This subordinate theme exposed the taboo of male-on-male and female-on-male rape. Although I had considered male-on-male rape due to the inclusivity of male participation in this research, I had failed to consider female perpetration of men highlighted by Thom's experiences of SAV by both genders. Although there is increased academia regarding the rape of males, the research regarding their experiences is limited and generally outdated (Widanaralalage et al., 2022).

Laskey, Bates and Taylor (2019) suggest that there is plenty of research evidence highlighting female victimisation. This research illuminated the paucity of literature addressing male victimisation of SAV. Historically, SAV has been associated with females and the dominance of power and control inflicted upon them by men. It is equally important to acknowledge that males can be victims of SAV and there appears to be a greater stigma and taboo associated with it compared to women. There is a lack of research utilising primary data for males who have experienced SAV which is possibly related to difficulties in recruiting men, and current knowledge is mainly founded on attitudinal studies, literature reviews, and archival research (Widanaralalage et al., 2022). At the time of writing this thesis, to my knowledge there was no primary data concerning male autistic SAV. This research reduces the gap in the literature and highlights the taboo which prevented Elijah and Thom's disclosure for fear of being laughed at and/or disbelieved. This is because of societal misconceptions that men are the abusers, and that they do not get abused because of their masculinity and dominance over women. Elijah and Thom presented with similar effects of SAV as the female participants but they experienced added challenges. The perception that only men can dominate and have power over females is fallacious as women can also be abusers. This is a controversial subject which is poorly understood and rarely considered. A female perpetrator forces a man to penetrate her with his penis either orally, vaginally or anally which is known as forced-to-penetrate (FTP) (Weare, Porter and Evans, 2017). There is limited literature in the area and it has implications for gender equality and bringing female perpetrators to justice:

In the current social climate we have come on leaps and bounds striving for equality between genders. However the fact a woman cannot be prosecuted for rape under the current UK legal system is not only a disservice to this strive for gender equality. It is also a kick in the face to all male victims of sexual abuse who are made to feel that their abuse is less important than a woman's as a man cannot pursue genuine legal justice for the ordeal they were made to undergo. This must change. (Petitions UK Government and Parliament, 2020, no pagination)

Indeed, change is vital and it has implications for male victims of SAV who have been perpetrated by females. Females are not brought to justice in the same way as males; thus, allowing them to get away with perpetration which does not give justice to men.

### **Loss of empowerment and control**

Each participant demonstrated the reality of the power and control that was taken away from them, and they expressed the danger they were exposed to by those in hierarchal positions. Daisy, Thom and Gwen were abused by their teachers:

My teacher... raped me twice and erm emotionally abused me as well. (Daisy)

Daisy reflected upon the rape and emotional abuse that her teacher inflicted upon her as he abused his position as an educator. Thom had similar experiences and he was caught up in a cycle of abuse by his teachers. He describes the extent of his abuse spanning his early childhood into adolescence:

I was introduced to the delights of anal sex [by teachers]. I say delights it was very unpleasant. I didn't feel that I had any choices or options. I didn't particularly understand what was happening or why: It's a lot to try and take in that two well respected teachers are abusing eight-year-old pupils. (Thom)

Thom was powerless and he had no control over what he was exposed to by his teachers whilst in primary school. He sarcastically expressed his feelings of disdain as he repeated the metaphor 'delights' regarding anal sex. The disempowerment took away his choice and there was no option other than to do as he was told. His confusion was possibly due to his abusive teachers being held in high regard and therefore, justifiable. Thom explained how his teachers controlled him:

[Thom and a girlfriend] We were encouraged to perform oral sex on both of them [male and female teacher] and both of us, on both of them, erm and on each other. Photographs were taken. That went on for a period of about two years on and off: Around ten, the male teacher who'd been abusing me... decided to move it forward and started taking me to public toilets where I would be encouraged to perform sexual acts on whoever was there. That would be anything from a couple of men to fifteen to twenty. (Thom)

Not only did Thom's teachers abuse him, they simultaneously coaxed him into a sexual relationship with his friend, and they all engaged in sex together. Thom reflected upon the role of his teacher who continued to disempower him as he made the decision to use him for cottaging. Subsequently:

The next incident I would guess was within three or four weeks of starting secondary school... music teacher, had a reputation: Whether it was because I already had a background of abuse or whether there was something about me that acted as a marker. I don't know. He very quickly singled me out... and he started abusing me during and after school. He would be taking me to his flat and introducing me to friends... and that was oral and full sex. He introduced me to another boy about the same age as me and we'd do photo shoots together: [Aged] ...eleven, eleven and a half, that carried on until I was thirteen as a regular thing. (Thom)

Thom's cycle of abuse continued at secondary school and he reflected. His teacher abused his position of trust, and his vocabulary symbolises that he had specific

characteristics making him a target for abuse. His teacher probably recognised the signs of an abused child and therefore, easy prey as he was already vulnerable. Similarly, Gwen was abused by her teacher in primary school aged “about nine or ten”:

[Teacher] ...he had me there on my own taking pictures. Obviously, me thinking he's an adult, he knows what he's on about. I should listen to my teacher. You're taught to listen to your teacher. You do as your teacher says. I wouldn't question it. (Gwen)

Gwen's teacher abused his position of power and trust just as Daisy and Thom's teachers had done. Gwen's perception is similar to Thom as he believed that being abused was acceptable because it was an adult telling him to do it. Gwen's language exemplifies the respect she had for teachers and she repeated 'listen' indicating that she obeyed them. She commented:

...it was just nude because obviously I was already in school uniform. It would just be like unbuttoning my blouse or unzipping my school dress or looking up my skirt. (Gwen)

Gwen's reference and repetition of 'just' regarding the sexual actions by her teacher seems to either undermine or deemphasise what she had experienced, and does not recognise the seriousness of it.

Daisy demonstrated disempowerment:

I knew it was happening [anal rape]. I knew for one I wasn't strong enough to get away. I wasn't strong enough to fight him off. ...due to what I like in the bedroom I was restrained [BDSM]. So, I couldn't fight him off even if I was stronger. (Daisy)

Daisy's loss of empowerment whilst engaging in BDSM runs counter to the expectations of this fetish because it is always consensual when practised correctly.

Couples engaging in BDSM use safe words agreed beforehand for safety purposes. When a partner says their safe word, it is a cue to stop the role play. The rules were not adhered to because Daisy should not have to defend herself whilst practicing BDSM. Just as Daisy had been anally raped, Gwen and Elijah endured it too:

If your pussy's no good then I'll use your mouth [boyfriend]:  
...actually, physically sick cus he wasn't letting up. I threw up on his carpet and he got angry that I was no good either way. So, he raped me anally. ...if I can't use your pussy and I can't use your mouth, I might as well use the last place. (Gwen)

Sexual penetration includes the vagina, anus and/or mouth. Gwen was not in a position to be vaginally penetrated and she was powerless in her attempt to defend herself. She physically reacted to sexual trauma as she vomited; therefore, her boyfriend did not penetrate her mouth but anally raped her.

He wanted to do anal and I wasn't very comfortable so I said no. He was as far as I can remember very aggressive and I was tied down to the bath where he penetrated me even when I was said no. (Elijah)

Elijah was overpowered by the rapist who restricted his movements. BDSM is his sexual preference, and it is apparent that he was engaging in the fetish whilst being raped. His experience is similar to Daisy's as the rules were not adhered to because when Elijah said 'no', his rapist disregarded his choice.

[Step-dad] ...he raped me on that bed and this is the thing it didn't just happen once, over and over again... (Elsie)

Elsie was disempowered by her step-dad and as she reflected upon his actions she said "I still struggle saying these words... *"I was raped"* ... [sigh]... She emphasised those words and her sigh is possibly due to sadness and/or anger. Elsie reflected, and

processed her experiences acknowledging that she had been raped whereby she had previously questioned it.

...it was always the same fucking thing: ...I would be in bed already asleep and he would come in, which means mum was asleep as well, oh my god..... That means she was there... sorry [gasp]. (Elsie)

As Elsie described her experiences, she fell silent. There was a stark realisation that her mum was there whilst she was raped. She emphasised 'was' and she paused, and gasped in shock. It suddenly resonated that she had been betrayed by her mum who could have protected her but she failed to do so. As her narrative unfolded, it seems that this is the reason why she dissociated whilst jumping timelines during her interview. Elsie knew that her mum was aware but she did not want to admit it, until now.

[Sobbing] I was in a park... I was in a park. I was walking home from meeting a friend, and he came out of nowhere. He jumped on me and said yow bitch pull your pants down, and I just didn't know what to do: He started fondling me and he he he he he started undressing me, and I was screaming to get him off but he wouldn't stop [sobbing]: [Penetration] ...vaginally and anally. I just didn't know what was happening. I broke down and I just didn't not know what was happening... I was in agony like it was horrible... he kept saying that I was a dirty little slut and that I was I was I was horrible and that I should deserve this and everything..... (Amy)

Amy's first experience of SAV happened without warning. She was utterly disempowered and she was robbed of control. At the start of her excerpt, she paused. Evidently, she was preparing herself because she was conscious that it would resurface painful memories. She sobbed and I felt her emotional pain. As Amy's rapist overpowered her, she tried to put up a resistance but to no avail. She was physically

and psychologically affected, and slut-shamed. Amy fell silent and whilst reflecting, she concluded that she deserved it and said:

He's still got that power over me. He's still got that control and it's just so *painful*... (Amy)

#### **Reflective box**

Amy bitterly sobbed throughout her description of her brutal assault and she struggled to get her words out as she stuttered. As I empathised with her, I experienced another poignant moment of 'thinking' and 'feeling' rape. As a researcher researching SAV, I felt the loss experienced by the participants which affected my sense of loss relating to innocence. I am at home with nature and take daily walks in the countryside, but Amy's experience has stayed with me. I never used to think twice about walking in secluded areas, but now whilst passing other walkers I automatically ask myself if they are a potential rapist. This goes against my perception of males because mostly, my experiences with them have been very positive. Whilst walking, I visualise what happened to Amy in the park and I can still hear her sobs in my head. In line with emotion work, Warr (2004) acknowledges the emotional impact on researchers as they are 'absorbing the voices and stories of research' (p. 586). I now avoid secluded spaces for fear of being attacked. Compared to what each participant has lost, my loss is inconsequential but it highlights the ripple effects of SAV.

#### **Discussion: Loss of empowerment and control**

This subordinate theme highlights the disempowerment of autistic individuals which can be the same for non-autistic people; however, the blend of autism adds to the complexity of SAV. Power can be related to heightened sexual assertiveness and esteem (Lammers and Stokes, 2018). Although Gravelin, Biernat and Bucher (2019) recognise that SAV is often motivated by power, they identify that there is limited experimental research examining the effect of power and powerlessness on the interpretations of SAV. There are many benefits to having power, but it can also be a corrupting force as the abuse of power is widespread in society, and the full extent of its effects are not well understood (Tobore, 2023).

The findings from this research support those of Carbajal and Praetorius (2020) as they acknowledge that the complexities associated with CSA are compounded by autism. The intersectionality of belonging to discriminated against groups or identities can complicate the experiences of oppression in situations involving greater legal, social or cultural barriers (Chaplin, Lovell and Twigg, 2019). Systemic inequalities contribute towards the unequal power relationships between different groups of people. Tobore (2023) states that high-powered people are invincible and unconstrained from the rules, and the emergence of their demeaning behaviour and false sense of superiority holds power over those who are less powerful.

This research exposes that those in positions of power abused their privileges and supports the research evidence concerning teachers who abuse their students. Grayson (2006) acknowledges that educators who sexually abuse their students tend to work with them individually and/or during extracurricular activities. This concurs with the experiences of Daisy, Thom and Gwen who, disturbingly, were affected by institutional powers. Students needing attention are typically targeted by educators as they recognise their desire for emotional bonding from an adult (Grayson, 2006), and this was possibly the case for Daisy, Thom and Gwen.

Each participant in this research was affected by the subsets of rape culture comprising loss of empowerment and control; sexual objectification; normalisation of SAV; victim-blaming; slut shaming; and/or disbelief upon disclosure. Kessel (2022) states that the definition of rape culture by mainstream feminist discourse is unrepresentative of the intersectionality of SAV and argues for the exploration of other aspects of power along with patriarchy including white supremacy, heteronormativity,

and capitalist exploitation, and not normalising male SAV against women. The words of Stiebert (2018) effectively sum up the superordinate theme of rape culture:

It is no accident that on-street groomers and sex-traffickers target people who are vulnerable on account of their gender, age, class, (dis)ability, and race, and who are deprived of a voice, social status, or economic autonomy and power. (p.13)

### **Sexual objectification**

Each participant was objectified and Amy, Thom and Gwen specified their sexual objectification. Amy said “I just felt like I was being used as a sex object”. Thom and Gwen’s use of metaphors powerfully demonstrated the meaning behind dehumanisation and objectification:

I was literally just a piece of meat. There was no romantic side to it at all: The big problem was I still didn’t have any self-esteem or self-worth. I think that was very much a consequence of the abuse because you are just a piece of meat. You’re not a human being. I’m not sure that if an abuser thought of a young child as a young child they could do what they did. It’s not something anyone could do I don’t think. ...from the abuser’s viewpoint they have to depersonalise the victim. So of course, the victim is going to feel depersonalised. So, I think because of that I was still very vulnerable. (Thom)

Thom’s repetitive metaphorical language ‘just a piece of meat’ symbolises the objectification he experienced impacting on his general sense of self-value and feelings of dehumanisation. He endeavours to rationalise why abusers dehumanise their victim, and concludes that they must go through the process of objectifying and making them less than human to be able to do what they do.

Similarly, Gwen felt depersonalised:

I'm just a toy that gets put down when it's broken. I didn't see myself as anything else: [Boyfriend] ...listing me off like I was some new product going on the market. She's good at this, she's good at that, and then when he rejected me I was like is there *something wrong* with me? Am I a defective product? That's when Danny called me a broken toy, and literally that's stuck with me. I'm a broken toy. I'm a broken toy. (Gwen)

Gwen's use of metaphorical language 'a broken toy' was referenced four times in one excerpt and evidenced sexual objectification. The idiom 'listing me off' symbolises that her boyfriend recited a list of her assets and liabilities. She felt like an object that was once useful but has since served its purpose and is now useless. She is unable to forget those words and this exemplifies the power of expressions and how they can either negatively or positively shape a person's beliefs.

Daisy, Elijah and Elsie did not discuss objectification but close interpretation of their data suggests otherwise:

I sent my energy to elsewhere [whilst being anally raped] and basically for him it must've felt like a technophilia because I wasn't life. I wasn't living there. I was somewhere else. (Daisy)

'Technophilia' indicates that Daisy objectified herself. The word was possibly mistakenly used and 'necrophile', a sexual act involving corpses would be apt. In that moment she did not exist in this life and for her abuser it would feel like raping a corpse. This interpretation links closely to the description of the murder and rape of her friend:

A friend of mine who was murdered in 2013... by a guy who I was also friends with: He was addicted to the snuff, hung her, and had sex with her afterwards. (Daisy)

Elijah was objectified:

...as far as I can recall I was tied I was just... tied tied up erm... I was actually tied down to the tent if I recall in a spread-eagled position [raped]. (Elijah)

Elijah paused twice in his attempt to remember what had happened to him whilst being sexually violated and it seems that he struggled to resurface his memories. Referencing 'tied' four times in succession suggests that he can remember his movement being restricted and objectified.

Elsie was a commodity:

[Step-dad] ...he kept accidentally coming into the room after I'd just had the shower: ...I was taking all of the inappropriate strokes, inappropriate touches, because he was groping me and stuff like that. Grabbing my arse when I walked out of the room erm always commenting on my breasts saying how they were bigger and better than my mum's... (Elsie)

Elsie's step-dad was calculated in his actions of grooming her. She recognised that his behaviour was intentional and 'inappropriate'. Elsie emphasised 'was' regarding being groped suggesting that she doubted whether it was abuse; yet, in this instance she acknowledges that it was. Her step-dad's behaviour fitted the subsets of sexual objectification including inappropriate and lewd sexual comments, non-consensual touching, and leering at her body. He then exposed her to pornography which commonly objectifies women:

He then started asking things like do you masturbate? How do you masturbate? Are you using any toys? What do you do when you use these toys? ...he decides to put porn on: Do I let him know it's affecting me? It's hard because it's the first time I'm seeing something like that. I'm actually intrigued. (Elsie)

Elsie's step-dad escalated his sexual behaviour towards her as he wanted to know her intimate details. She held two conflicting thoughts whilst being introduced to pornography. Firstly, it was difficult for her to watch it and secondly, she really wanted to but she did not want to participate with him.

### **Discussion: Sexual objectification**

This subordinate theme emphasised the sexual objectification and dehumanisation of each participant, and they are closely linked with each other. They negatively impact upon an individual's humanity which was evidenced by the participants as they felt undeserving of being treated humanely. People who are sexually objectified are treated as a thing (Stock, 2015), and this has implications for autistic and non-autistic individuals. Consideration deserves to be given to the less informed concept that males can experience dehumanisation by other men and/or women. This was Thom's experience as he was dehumanised and objectified by both genders. Conventionally, it is deemed that men objectify women, but due to gender equalities it has been recognised that the male body can be objectified by females (Waling et al., 2022).

Sexual objectification is an umbrella term for a diverse range of experiences that make someone feel as if they are merely a body that exists for the use and pleasure of others. (Wesselmann, 2021, p. 841)

Sexual objectification can either be hostile or benevolent, and blatant or subtle, and similar to other forms of sexual aggression (Loughnan and Pacilli, 2014) which was demonstrated by the abusers of the participants in this research. Sexual objectification occurs in various forms of media, and individual encounters which are prevalent on a daily basis (Xiao et al., 2019). They differ in context from the home environment,

workplace, and public spaces and may take the form of catcalls, sexist jokes or SAV (Wesselmann et al., 2021). Sexual objectification can contribute to poor mental health; eating disorders; depression; and impact on normal sexual activity (Szymanski, Moffitt and Carr, 2011). Xiao et al. (2019) explain that sexually objectified women progressively internalise the objectifying individual's perception of their own body. Objectification may be harmful if the judgements are internalised and subsequently, the abused self-objectifies (Kellie, Blake and Brooks, 2019) which was the case for Gwen:

I had quite long hair and I cut it, boy cut short. No one will want me if I've got scars all over my body. No one will want that. I'll be protected because I won't be that pretty thing anymore. I'll be skin and bone. I didn't mind being that broken toy because then people will leave me alone. I can die without people thinking oh that's a shame, you know they wouldn't think that about this little, tiny broken thing. (Gwen)

### **Blurred lines: This Is normal - Isn't it?**

Gwen, Daisy, Thom and Elsie were groomed and/or coerced into believing that SAV was normal because it was instigated by people they trusted. Gwen and Daisy believed that all women are sexually violated highlighting the normalisation:

I figured that was just what women had to put up with [SAV].  
(Gwen)

Everyone must go through this [SAV] and it was just generalising it and because he'd also said don't worry this is fine. I'm allowed to do this *oh it's like ok, fair enough* then you just accept it.  
(Daisy)

Daisy felt that her abuser had generalised SAV because of his reassurances, and it was not disputed because as she emphasised her words it demonstrates normalisation.

I didn't recognise them as abusive [relationships]. I think that's the other side of the conditioning of abuse at a young age. It's not abusive. It's just what happens: I knew it was naughty. I knew I shouldn't be doing it, but it was an adult telling me to do it so it was ok. (Thom)

Similarly, Thom was unaware of what an abusive relationship comprised and acknowledged that it was a consequence of being conditioned and normalised in childhood. He held conflicting views because although he recognised that what he did with his abusers was not a good thing, he also felt that it was justifiable because he was told to do it by an adult.

[Step-dad] ...he had started grooming, started preparing from when I was fifteen and taking little steps like wearing me down, making me feel like it was normal you know, and it's ok. It's what he does or it's normalised me to that kind of behaviour....: ...I'd been conditioned to that kind of touch between families was ok, that it was normal, didn't feel normal but its ok we're family, but it's not supposed to be. (Elsie)

Elsie's step-dad groomed her into believing that inappropriate sexual behaviour was acceptable within the family unit. However, she felt conflicted because although it was normalised, she perceived it as not being normal.

**Discussion: Blurred lines: This Is normal - Isn't it?**

This subordinate theme elucidated the confusion experienced by each participant as they questioned their abuse because the lines were blurred by people they trusted. The research findings substantiate that autistic people are highly prevalent targets within rape culture compared to the general population. This is because of their symptoms of autism and captures the complexity surrounding autism and SAV. Chaplin, Lovell and Twigg (2019) acknowledge the necessity of highlighting complexities to understand the factors associated with inequality and marginalisation, and the requirements needed to build the resilience of marginalised individuals. Crenshaw (2016) detailed the need to eradicate the intersectionality of oppression and violence for those who are marginalised. She suggests that the way forward is to initiate a change in our own behaviour, and to listen to the views of vulnerable individuals to get a better understanding of their challenges faced on a daily basis.

### **Victim-blaming**

Each participant blamed themselves for their experiences of SAV and, in some cases, they were blamed by those in hierarchy. Daisy demonstrated how she was blamed by police officers for her experience of SAV:

I was dating this lad, he was *evil*. ...violent throughout the relationship. ...he raped me on school property: [The police said] I was taking advantage of a lad with learning difficulties: They looked back on it, CCTV, and they made the decision that I consented, regretted it, and then made up this false story and then that's what they came back with, you were in the wrong place at the wrong time. (Daisy)

Unbeknown to Daisy, she dated a rapist and her emphasis on 'evil' characterises him and his actions towards her as he sexually violated her. Undoubtedly, she is a rape victim, and it is feasible to suggest that she felt disillusioned by the conclusion made

by the police. Evidently, she fell prey to the culture of victim-blaming highlighting that the CJS can fall into this category and she stated “they’ve got to stop victim-blaming...”.

...I felt guilty was because I was sleeping with a total person [stranger]. (Elijah)

Guilt is associated with doing something wrong, and it is a common moral emotion that can be related to SAV. Elijah compromised his moral standards and judged himself for having sex with someone he did not know.

I question whether it was abuse cus I could’ve stopped it couldn’t I? If I’d wanted to. So obviously I didn’t want to. (Thom)

It’s probably my own fault for walking with my head phones in. Well I say that. No. No victim-blaming because that’s everywhere at the minute and it makes me angry when they say it about other people. So, I’m not going to say it about myself. I’d walk home and I had a man push me into bushes and try and force himself on me. (Gwen)

...this was my fault [rape]: I shouldn’t have walked through the park. (Amy)

Similarly, Gwen and Amy blamed themselves for their experience of SAV because of walking home alone. However, Gwen contradicted herself and she quickly retracted her comment. She indicates that victim-blaming is a buzzword regarding rape culture. She felt anger which is an intense emotional response, and in Gwen’s case it is possibly associated with feelings of frustration at victim-blaming as it invalidates a survivor’s experience.

Daisy and Elsie demonstrated how they were overcome with self-reproach:

[Her rapist whilst at school] ...now he's in prison for five years cus he raped a twelve-year-old girl: I found this out earlier on this year: *I lost it. Completely lost it. If they'd believed me the first-time round, that girl wouldn't have gone through it... it broke me,* and I take a lot of it on board that it was all my fault. I should've pushed it further. (Daisy)

I didn't feel like my sister was in danger you know. I felt like I was guarding, protecting her you know, keeping his attention on me meant that she was safe...: ...and I said but I saved you: ...she said but you didn't Elsie, and oh my god did that break me [crying]. (Elsie)

Daisy and Elsie felt responsible for the effects that the perpetrators had on their victims. They blamed themselves because they believed that they were unable to protect them. There is a synergy between their reactions and they both referred to feeling broken. Daisy experienced frustration at being disbelieved and Elsie cried, highlighting her sense of guilt.

### **Discussion: Victim-blaming**

This subordinate theme revealed how four participants blamed themselves for their endurance of SAV. Female and male victims of rape are expected to put up a resistance to their rapist (Ostermann and Watson, 2024). If not, they are often victim-blamed and may experience negative reactions within their social surroundings (Mulder and Bohner, 2022). Rape victims are uniquely vulnerable compared to other victims of interpersonal crimes as they tend to be blamed for the crime of SAV inflicted upon them (Gravelin, Biernat and Bucher, 2019). This theme highlighted that victims may also self-blame. There are widespread cultural scripts regarding the way male and female victims of SAV are expected to act during an offence; however, reality deviates from those suppositions as victims tend to respond contrary to what is

expected (Ostermann and Watson, 2024). Kazmi et al. (2023) advocate the importance of challenging rape myths because of the influence it has on how people respond to victims. The prototypical gendered response to victim-blaming threatens an individual's masculinity/femininity as men blame victims more, and females do not blame victims as much when their gender identity is at threat (Gravelin, Biernat and Bucher, 2019).

Despite scepticism that rape culture does not exist, this research highlights that it is not a myth. The sceptics are those who blame the victims and make excuses to vindicate the perpetrators. The myths need to be dispelled to expose the truth behind the secrecy of SAV. The reality beyond the myth is indicative of the society in which we live.

## 5. Specialist support services: Where are they?

**4.7 Table 5: Superordinate theme and related subordinate themes**

Subordinate theme	Daisy	Elijah	Thom	Gwen	Amy	Elsie
Counselling isn't for me	✓		✓	✓	✓	✓
Retraumatization				✓	✓	✓
I don't understand my emotions: Do you?	✓	✓	✓	✓	✓	✓
Communication misunderstandings			✓	✓	✓	
The mental connection is the most important	✓		✓		✓	

### Counselling isn't for me

Each participant was referred to support services to access therapeutic interventions. All of them except for Elijah acknowledged that counselling was not particularly for them.

For Amy:

I ended up in hospital [place name] for two weeks and then I ended up in a teenage unit for mental health and it was really horrible. (Amy)

Gwen described the fragmentation of the therapy system in the UK:

The system for therapy in this country is so broken and people can get out of it so easily. I don't think they realise that either, how many people will manipulate them to get out of seeing them. So, they think oh, we've helped this many people. No. You haven't. A quarter of those people will've been like I'm going to tell you what you want to hear today because I don't want to be here... (Gwen)

Gwen, Daisy and Thom learnt the "script" that therapists adhere to whilst providing therapeutic support for their clients. Each of them told their therapist what they wanted to hear to disengage from therapy:

I've been to counsellors since I was thirteen. I soon learnt that counselling wasn't really for me. You say the right things, they get off your case... [laugh]: It's the same with doctors. I know what I need to do if I want the pills again. I also know what to do if I want to come off them. You quickly learn the script that they have to follow and you use it to play your own game... (Daisy)

Daisy laughed as she reflected upon her counselling experiences and it seems that she is making a mockery of it. This is possibly related to its ineffectiveness after attending for many years. The idiom 'play your own game' and the word 'script'

indicates that she knew exactly how to act, and what to say in order for the therapists to forgo her treatment. She applied the same script with other professionals:

I was sent to the crisis mental health team and they met with me once and then I never saw them again: Do you have suicidal thoughts? *No*. Do you have self-harming thoughts? *No*. So went home and slashed my wrists. (Daisy)

Whilst asked about her mental health and safety requirements, Daisy emphasised and repeated the word 'no' in answer to the questions because she knew that it was an effective strategy to end her therapy.

[Autism] ...if they'd had known what that meant, and if they had found a therapeutic mode of operation that worked with an autistic mind possibly. But as there isn't a mode of therapy [laugh] that works with an autistic mind, probably not. Talking therapies don't work for autistic people generally because we know how the games played. We know what the rules are so we just ignore it. We just tell people what they want to hear. (Thom)

Thom perceived that talking to a trained professional is not particularly beneficial for autistic people. He had possibly previously been referred to numerous talking therapies which were unproductive. He mocked and laughed about them because he deems that therapists do not understand autism and how autistic minds work. Similar to Daisy, Thom references 'games' and he knew how to play them to disengage from therapy. They both responded in the same way to the therapists and there is a palpable air of defiance in their excerpts:

If you tell me I've got to see that person over there pphhh fuck off. Don't care. I'll see them. I'll play em up. I'll wind em up. I'll give em all sorts of bollocks: Autistic minds don't work like other minds so I can only talk from an autistic point of view. Therapeutic services, counselling, don't work, waste of time for most autistic people. (Thom)

Messing with therapists is fun cus you can sit there, you can sit in silence cus I don't do well with hospitaesque buildings. ...I don't like it and I'll sit and be mute. After about forty-five minutes they'll stop asking questions and they'll just look at ya. If you start to laugh when they start looking at you, it terrifies them. It's hilarious [laugh]. (Gwen)

Evidently, professional therapeutic support was uncomfortable for Thom and Gwen. From Thom's autistic perspective, therapeutic interventions are mainly ineffective for autistic individuals because their minds work differently. He possibly deems that the same mode of therapy is given to autistic and non-autistic people and therefore, pointless.

The best therapist I've ever had is me... I've just needed the tools: I don't want advice. I just want to talk stuff out so it's not in my head: That's what I think most autistic people want and unfortunately the way support, and therapy, and counselling works now is you go along, you get a referral and get allocated a therapist. The minute that happens I go pphhh! I'm not getting on with them. (Thom)

Thom reflected upon himself as a therapist. He referenced 'tools' suggesting that he required help to enable him to do this, but he did not elaborate on the required tools. Thom does not benefit from unwelcome advice from professionals, and he has a fixed mindset as he does not consider trying therapy again, and immediately puts up barriers. Similarly, Gwen does not welcome unsolicited advice:

I didn't want to talk about my abuse. I wouldn't let them go there: I don't want to sit for an hour with you every single day to try and work through my trauma that I work through better on my own. (Gwen)

It seems that Thom and Gwen feel that they are better positioned to work through their own trauma without the support of professional interventions. Also, as previously

discussed, Daisy found her own route of therapy to be effective, and Thom and Gwen believe they are their own best therapist. This is thought provoking because they had initially disconnected from themselves, but there came a point where they reconnected. The importance of mental connection is discussed later in this section. Possibly, their lack of trust in therapists enforced their road to recovery as they had endured so much trauma that the only person they could trust was themselves.

Thom describes his loathing of psychologists and therapists:

...not in a therapy session, not in a guided learnt thing. Just talking like having a conversation that's the best therapy we can have, and that doesn't have to be with a trained therapist. It doesn't have to be with a qualified person. It certainly doesn't have to be with a psychologist because they all come with too much baggage. If I'm in distress, what I want to do is have a conversation. I don't want a therapy session. I want to have a chat and I don't care who I chat to so long as I trust them, and the chances of me trusting a psychologist are nil. The chances of me trusting a therapist are very very slim because most of them are idiots. (Thom)

Thom was explicit as to why he would not benefit from therapy, and 'we' suggests that he is speaking on behalf of other autistic individuals. 'Trust' was poignant because throughout his life those whom he trusted, abused him. Therefore, it is unsurprising that he has trust issues with therapists and psychologists as he possibly had previous negative experiences with them. It seems that he perceives them as 'idiots' due to their lack of understanding of autism. However, at the time of therapy, Thom did not have an autism diagnosis and it is feasible to suggest that it contributed to the ineffectiveness of therapeutic intervention.

My parents were contacted by social services who forced me into CAMHS erm counselling: ...a support group for troubled children. It wasn't specific in like abused children, it was like very

general, just a little group that you would go and sit in. I hated it. I went once. (Gwen)

Gwen felt compelled to engage in therapeutic interventions:

I don't do well with *talk* therapies. I don't see the point in them, even if they're not like things like CAMHS. I won't go near those places. It's not just because I had a bad experience with the people that I spoke to there, and how they treated me. Obviously, I was quite mature for my age. They treated me like a child when my brain wasn't that of a child. I was like you're being a knobhead, like stop treating me like that. (Gwen)

Gwen emphasises 'talk' regarding ineffective therapeutic interventions and possibly related to her social and communication difficulties. Her maturity was disregarded and she felt patronised. She believed that the therapists treated her in the same way as her opinion of them, 'a knobhead', meaning they were idiots concurring with Thom's viewpoint.

...what I needed to do was to talk it through with someone like like a therapist sort of situation to make me feel better: ...sometimes all therapy is is just one person talking and the other person listening. (Elsie)

Similar to Thom, Elsie wanted to talk through her trauma informally with someone who would listen and offer her reassurance akin to a therapy session, but unconventional.

### **Discussion: Counselling isn't for me**

This subordinate theme exposed the barriers faced by the participants whilst seeking therapeutic support and echoes the existing literature (Carbajal and Praetorius, 2020). There is a stark lack of research evidence addressing the effectiveness of therapeutic support services for the autism population. Furthermore, this research highlighted that SAV specialist support services were lacking for autistic individuals, although they are

more predominant for the non-autistic population. This deserves consideration, particularly as autistic individuals are highly susceptible to mental health problems, self-injury, and suicidality compared to the general population (Camm-Crosbie et al., 2019). Additional challenges are faced by autism people whilst accessing therapeutic interventions due to disjointed service provision. Camm-Crosbie et al. (2019) deem that it is unlikely that they will be able to access support and treatment for their problems (Camm-Crosbie et al., 2019). Even if they do receive mental health provision, current support does not meet their psychological needs, and the literature is deficient regarding the preferences of autistic individuals in receipt of therapy (Jubenville-Wood et al., 2023). It is crucial to understand the barriers that they may face, and the resources must improve the outcomes of their social, physical and mental health (Malik-Soni et al., 2022). Treatment interventions for autistic people need modifying as children who endure SAV are at a higher rate of PTSD compared to those who have not experienced it (Carbajal and Praetorius, 2020). This concurs with Chivers-Wilson (2006) stating that the high prevalence rate of PTSD in SAV survivors is alarming, and a strong indicator that treatment needs to be improved due to the inadequacy of therapies:

Physicians, therapists, law enforcement agencies, and family and friends must work together to find the meaning of recovery from the perspective of the survivors and to understand what conditions will facilitate growth and recovery. When the therapies available to treat sexual-assault-related PTSD are brought together during the right stages in the recovery process to form a comprehensive treatment of the highly individual survivor, greater success in decreasing the rate of PTSD associated with sexual assault may be achieved. (Chivers-Wilson, 2006, no pagination)

Some of the participants explained that their therapist/s lacked autism knowledge which resulted in ineffective therapeutic support. This concurs with Camm-Crosbie et al. (2019) as they clarify that generally mental health professionals are untrained in recognising and understanding autism. Malik-Soni et al. (2022) advocate strengthening healthcare service provision by the stakeholders to improve medical training for the care of autistic individuals; increasing societal awareness of autism; promoting the research of tools for autism screening diagnosis; and treatment. Consideration deserves to be given to the service providers. If they understood autism, the participants in this research may have been referred to services that understood their needs, and possibly signposted to autism diagnostic assessment services.

It is important to note that the participants did not have an autism diagnosis at the time of therapy. They had other diagnoses which may have been taken into consideration, and had possibly been mistreated. Daisy was adamant that her treatment would have been effective if she had an autism diagnosis. Regarding her therapists she said “they just treat everyone the same” indicating that they used a standardised approach. It is inappropriate to utilise a tick box exercise for those with the level of deep-rooted trauma that the participants experienced. Franklin, Brady and Bradley (2020) advocate for disabled children to ‘see me, hear me and understand me’, in a concerted effort to detach from a tick-box culture of medicalisation, categorisation, psychiatrising and ‘othering’ to gain insight into their world and to challenge the barriers to support. A one-size-fits-all approach is unsuitable due to the different ways a person may experience the challenging intersects between violence, intervention and disclosure (Chaplin, Lovell and Twigg, 2019).

Autistic individuals who are mainly undiagnosed frequently access therapy (Marshall, 2014). Consideration needs to be given to the effectiveness of therapeutic interventions if they had an autism diagnosis at the time of therapy. Autism manifests in various ways and autistic people have similarities and differences in how they are affected. As autistic individuals may experience the world differently to non-autistic people, it is important that they are referred to a therapist who can effectively support them. Autistic individuals can significantly impact upon a practitioner's way of working which can affect the self-worth of the therapist and their client (Marshall, 2014). This was Thom and Gwen's experience as they described how they had intimidated their therapist/s to disengage from the therapeutic process. They put up resistance towards them as a way of taking back some control. Simply put:

Kinds of people who are medicalised, normalised, and administered, increasingly try to take back control from the experts and the institutions, sometimes by creating new experts, new institutions. (Hacking, 2007, p. 311)

## **Retraumatization**

Gwen, Amy and Elsie were retraumatized by therapeutic interventions:

[Therapy] When I started to go to those sorts of things and try and talk to people, my abuse at home got worse: That's always the question that always stunts me. I'm like I don't know why any of it happened. I don't know why I'm upset. I don't know why I can't handle emotions. But why? But why? It would make me freak out more and more every time. (Gwen)

Gwen was retraumatized by therapy which had a domino effect at home. Her repetition of 'I don't know why' and 'but why?' suggests that the therapists kept asking her the same questions that she could not answer. Possibly, Gwen may have had a better

experience if she had an autism diagnosis at the time of therapy because evidently, she struggled with questions regarding her emotions. She demonstrates that she was retraumatized 'physically' and 'mentally' by therapeutic interventions due to repeated psychological exposure to previous trauma:

You don't want to have to physically go through it and then mentally go through it: Over and over and over again: [Therapists] They don't realise how much it hurts to kind've bring back those memories from when you're younger cus some people don't use it as like I make a joke out of it. I make things like oh well it doesn't really matter. Some people don't do that. Some people will sit and cry and if they have to do that four times that's like they've experienced it five: I struggle a lot with meeting new people. So, if you're transferred from pillar to post and you have to see people all the time, it just *exhausts* you: I don't want to tell my story to fifty different people: ...you're lucky if I'll tell one person: ...it's having the same session over and over again. I'm not growing from that. They might be like the new person that comes in like, oh I've never heard this before, but I've *said* it before. (Gwen)

In comparison to most people, Gwen makes light of her trauma. The idiom 'pillar to post' indicates that she was moved from one professional to another without progression, and intensified by her social and communication difficulties. She emphasised 'exhausts' exemplifying how revisiting her trauma was emotionally overtaxing. There is a hint of sarcasm referring to meeting with 'fifty' people. Whilst being assigned a new therapist, they welcomed what they thought was first-hand knowledge, but Gwen emphasised 'said' suggesting that she had already disclosed that information many times before which was unhelpful.

[Place name] ...it's a mental health hospital for people with psychological disorders... it caused me to have my mental breakdown. (Amy)

Didn't cope: ...I would attempt to have some sort of level therapy course when come to broach that subject because that's where therapists seem to see that my emotional state stems from, what had happened to me, and I have to address it in order to get better. I couldn't cope with it so I self-harmed: I would cut. Erm I had a couple of suicide attempts: But I'd had eight sessions with them and we realised that it was just wasn't going anywhere. (Elsie)

Amy and Elsie's experiences of therapeutic interventions resulted in mental distress. Elsie's therapists deemed that her 'emotional state' was rooted within her trauma which had to be addressed to enable recovery. This approach was ineffective and she was retraumatised. Elsie repeated that she was unable to 'cope' and she inflicted self-injury and attempted to take her life. 'We' suggests that it was agreed by herself and the professionals that her treatment was ineffective.

### **Discussion: Retraumatization**

This subordinate theme is representative of retraumatization by therapeutic interventions. Therapeutic retraumatization can also affect non-autistic individuals. Curran et al. (2019) acknowledge the limited quantitative research directly addressing therapy that may be potentially harmful. Many clients report adverse effects of psychological interventions due to "...therapists misbehaviour, hindering aspects of the relationship, poor treatment fit, and negative impacts of treatment" (Vybiral et al., 2024, p. 279). Adverse therapeutic processes include the behaviour of the therapist such as rigidity, being overly controlling, and a lack of knowledge impacting on clients as they may feel disempowered, silenced, and devalued (Curran et al., 2019). This supports the findings from this research. Whilst supporting autistic individuals the use

of language is important, particularly as a derogatory comment may further traumatise them (Gravitz, 2018).

Untimely disclosures to therapeutic interventions will probably increase further perpetration (Alaggia, Collin-Vézina and Lateef, 2019), and this was the experience of the participants in this research. Their mental health deteriorated due to inaccessible support services adding to their cumulative oppression. It had devastating repercussions on their psychological and physiological well-being. In some cases, it exacerbated their mental health problems resulting in additional self-harm and suicidality. The reasons are likely to be complex as to why autistic individuals lack treatment and support (Camm-Crosbie et al., 2019). Consideration deserves to be given to the complexities associated with autism, SAV and PTSD whilst supporting a survivor.

### **I don't understand my emotions: Do you?**

Each participant articulated how they struggled to understand, process and express their emotions:

[Emotions] ...I really don't know what they are. There's some that I've learnt like I know when I'm happy. I know when I'm angry. I know when I'm sad. I know the basic but I couldn't tell you if I'm distraught. (Daisy)

My emotions are quite extreme for instance I can get angry quite easily. (Elijah)

...autism and emotion are not happy bedfellows: I don't necessarily know what I'm feeling or I can't really explain what I'm feeling emotionally or physically sometimes. (Thom)

Thom's figurative use of language is interesting as he associated 'autism' and 'emotion' as incompatible 'bedfellows'.

I've always kind've struggled with my own emotions and processing my own emotions and I've really struggled with processing other people's emotions: When I get overwhelmed with emotion I just end up trying to kill myself because I can't deal with it. (Gwen)

Gwen's processing capacity and inability to effectively express herself safely suggests that it was more than a cry for help, but a considered intention to end suffering rather than communicate it.

So, although I can say that I've felt this emotion, I wouldn't know necessarily know what that emotion is or, if it was real, or if it's just my reaction to the memory of the emotion. (Elsie)

Possibly, Elsie has alexithymia as she felt emotions but does not particularly identify with their meaning.

Although Daisy has a grasp on 'basic' emotions, she was unable to identify complex ones which negatively impacted upon her treatment:

My doctor referred me to AXESS which is a sexual health or sexual abuse related counselling service which specialise in it, and to be fair they were good... But, I knew for a fact that if I had my diagnosis then, they would've been so much better because they were focusing on so how does this make you feel? I don't know. I don't have any grasp on feelings. I don't know what they are so if I'd got a diagnosis they'd have gone in a totally different direction. (Daisy)

Daisy felt that her experience of therapeutic services would have been more effective

if she had an autism diagnosis at the time of therapy. Her treatment was standardised as it focused on how she was feeling which was ineffective because she has no concept of feelings.

There was a palpable air of hopelessness as Amy described her emotions:

I just feel so afraid to cry about my emotions. I'm scared to show my emotions: I just didn't know how to deal with my emotions: I don't deserve to feel these emotions [sobbing]. I feel anger, I feel I feel upset, I feel, I feel like like I'm worthless. I just don't know what more I can do. I've tried moving on. I can't. It's just too painful, it's just too painful..... I really am sorry for crying: I'm not very good at describing what I've gone through because of how I can't open up to people. (Amy)

There was a dichotomy in Amy's narrative. She said that she had difficulties in describing her experiences, yet she gave a highly impassioned description of her trauma. Despite difficulties in opening up to people, Amy fully told her story. She used emotive language as she articulated her fear of expressing and managing her emotions because she does not know how to. There was a sense of helplessness as she sobbed and she felt undeserving of emotion. Possibly, she was emotionally unstuck and unable to help herself. She reflects, and the silence was interrupted by her sobs. Amy apologises for sobbing which may be due to feelings of shame, unworthiness, and/or because she did not want me to feel uncomfortable.

### **Discussion: I don't understand my emotions: Do you?**

This subordinate theme highlighted that each participant had difficulties identifying their emotions. Autistic individuals may struggle to communicate and understand emotion (Molnar-Szakacs et al., 2009). Rump et al. (2009) acknowledge that they may

lack the mental representations of basic emotion, and this was expressed by Daisy. It is worth considering alexithymia which is the inability to identify, express, verbalise emotions, and difficulties in differentiating emotional states from bodily sensations (Fitzgerald and Bellgrove, 2006). Emotional processing problems may reflect co-occurring alexithymia and up to 50% of autistic people experience it (Kinnaird, Stewart and Tchanturia, 2019). Understanding emotions are central to prospering in a composite world of social interactions (Molnar-Szakacs et al., 2009). Difficulties faced by autistic individuals whilst interacting with non-autistic people may be the failure to recognise the emotions and mental states of others, and non-autistic people may struggle to read those of autistic individuals (Brewer et al., 2016). Recognising emotional facial expressions are essential whilst forming interpersonal connections, and a main indicator to understanding the intentions of others (Rump et al., 2009). Non-autistic people interacting with autistic individuals need to have awareness of the idiosyncratic nature of their emotional expression (Brewer et al., 2016).

Although most of the participants in this research understood basic emotions, they struggled to understand and effectively express the more complex ones. However, they demonstrated deep levels of outward emotion which was displayed via their body language and comprised crying; sobbing; and/or laughter. Anger was a common theme between each participant. There is a contrast with the less emotion-laden accounts by individuals who just tell their story, or use humour, because they may receive a less empathetic response from the listener. When we expect people to be upset by an experience, arguably we behave differently when they are not.

### **Communication misunderstandings**

Thom, Gwen and Amy experienced communication misunderstandings between themselves and their therapist/s:

...whether that was my perception skewing what the therapist was saying, that was the feeling I got from the therapist. It's happened. Just deal with it. Move on. (Thom)

Thom was uncertain whether he had correctly perceived what he had been told by his therapist or if it was his bias. His language suggests that his therapist had devalued and dismissed his experiences.

I had a therapist once be like where did you get the cuts on your arm... Claire's. ...picked them up from Claire's. Where do you think I got them from? Don't ask stupid questions: [Therapists] If you go into a room with someone that's never been abused in their life, and they ask you stupid ass questions you are just going to start taking the piss out of them: You know that I've been abused or that I'm abusing *myself*, why would you ask me that? People that have been through abuse know not to word it that way, they know that it sounds like a fucking stupid question. (Gwen)

Gwen reflected upon a question asked by her therapist which irritated her. It was obvious that she had self-harmed and she responded sarcastically. She was angry by their questioning because of the stupidity of them. She felt that therapists who had experienced abuse would be more empathetic to how they worded their questions.

...they try and make me explore my thoughts that I've shut off. When I try and explain I've shut them off for a reason, they're like yes, but we need to explore that. But *I don't*. That's a portion of my life that is done and therapists never get that. They never understand that there are some corners that you just don't wanna go in. (Gwen)

Gwen was unable to effectively communicate her needs to her therapists, and she distinctly implies that she does not want to revisit those traumatic experiences.

'Corners' suggests that she compartmentalised her trauma. She emphasised 'I don't' regarding not wanting to enter them making it clear that it is beyond her limits. The therapists were unable to grasp this concept and it broke down their reciprocity.

I had to go to CAMHS and they suggested cognitive behavioural therapy, but because I didn't open up to them as much as I wish I would've done, they did not have the right techniques in place to support me... (Amy)

There is a sense of regret as Amy reflected upon her experiences of therapeutic intervention. Referencing 'wish' exemplifies that her treatment might have been more effective if she had the ability to be more transparent but evidently, the support service did not have the skills required to help her do so.

### **Discussion: Communication misunderstandings**

This subordinate theme exposed communication misunderstandings between the participants and their therapist/s. Daily miscommunication can be difficult for non-autistic people, but it may be intensified for autistic individuals due to the symptoms of autism. Misunderstanding communication can exacerbate anxiety levels in autistic people and it has implications for clinical practice (Robertson et al., 2018). If therapists do not understand how autistic individuals communicate and express their emotions, and autistic people are confused about their emotions, it could have connotations for the effectiveness of therapeutic interventions. Consideration deserves to be given to the body language of an autistic person displaying self-stimulating behaviours. Stims are exhibited in various ways including repetitive and complex body movements and/or objects, head banging, arm and/or hand flapping/flicking, rocking, jumping, spinning or twirling (NAS, 2020). These behaviours can be grounding especially whilst experiencing sensory overload or feeling overwhelmed. Non-autistic people may not

inherently understand that stimming can indicate how an autistic individual is feeling. Non-autistic people stim but it is subtler compared to autistic individuals because their mode of self-expression may be more visible.

It is important to improve communication to enable effective therapeutic interventions, particularly if distress and psychological symptoms are heightened (Popa-Velea and Purcărea, 2014). Therapists may consider discussing misunderstandings with their clients to strengthen the client-therapist relationship, and it may be a valuable therapeutic experience for the client (Rhodes et al., 1994).

Johnson (2009) undertook a study and she empathised with a participant who felt uncomfortable being supported by people who had no knowledge about her experience, and the participant challenged whether Johnson was doing the same. She reassured her participant that she came from a similar background, and there was a noticeable difference in her approach towards her and the research, as she was not 'an outsider looking in' (Johnson 2009). Similarly, Gwen felt that it would be beneficial to talk to someone who had "actually suffered abuse", her perception being they would have a deeper level of understanding compared to someone who had "never been abused in their life".

### **The mental connection is the most important**

Daisy, Thom and Amy did not naturally connect with other people and they found their own path to recovery. For Daisy:

...writing poetry, that's the only way I could deal with it: [Poem]  
When I finished, it was a weight off my shoulders: I can move  
on, and then that's when the recovery process started. (Daisy)

The power of 'poetry' was significant as Daisy articulated her trauma via this mode of creativity. She felt unburdened referring to the idiom 'weight off my shoulders' and this was the catalyst for her recovery. Furthermore:

The thing what helped me the most was the horses, *they were brilliant*: Whenever I'm on horseback it's a bubble. I'm totally connected to them and going for a gallop or a good jump is the most therapeutic I've ever known: Horses pick up everything. *Absolutely* everything and they react in the best ways: Connect to the horse, connect to his energy and away you go: Seeing that connection there, you can feel the energy drawing you in which is inviting you into their personal space. (Daisy)

Daisy innately connected with her horses emphasising their brilliance and evidently, an effective mode of therapy. Horses are symbolic of freedom and it is possible that she felt liberated whilst on horseback. She emphasised 'absolutely' suggesting that the horses sensed that she had experienced some form of trauma as they have the ability to recognise human emotions, and they effectively responded to her experiences. 'Bubble' suggests that Daisy was protected from the outside world. She entered the horse's personal space exemplifying mutual trust and respect which was missing with her human interactions.

After the suicide attempt I just sat down with him [horse] and this is what I'm meant to be here for: I knew at that point that that horse loved me: The idea that autistics connect more with animals than they do with humans [whispered] *because they're a lot simpler*. You know where you stand. (Daisy)

Daisy realised that her horse was the reason for living, and possibly fills a missing void in her life. She emphasised and whispered '*because they're a lot simpler*' suggesting

that horses are uncomplicated and supported by the idiom 'you know where you stand' suggesting the unpredictability of people.

I'm not interested particularly in physical sex other than to scratch an itch. It's the mental connection that's the most important: ...breath play, so we would strangle each other erm... and it was very enjoyable. In a way... it gave me the feeling of connection that the abuse was taking away because when I was being abused I wasn't there. There was nothing there other than stuff happening. This was very intense, very passionate, very stimulating intellectually. (Thom)

The idiom 'scratch an itch' suggests that Thom only had sex to satisfy his sexual urges. For Thom, mentally connecting was fundamental and he achieved it through engaging in BDSM. As previously discussed, Thom dissociated whilst being abused. He recognises that feeling connected to someone is what was missing during the abuse. The connection he made with his partner during breath play was a powerful, impassioned and an energising experience giving him the mental connection he desired.

Amy's connection with me in her interview was poignant as it was the first time she had been believed:

...feels weird that's all for someone to believe in me and wants to support me. It makes me feel some kind of positive reinforcement. It makes me feel that someone wants to listen to me, and someone wants to help me, and that's what I want people to experience: It feels such a relief that someone actually believes me because there's a lot of people out there that don't even want to know my story. I need to tell it because I need to let other autistic people know that it's ok for them to speak out. (Amy)

Amy's experience of being believed feels surreal because her past experiences of disclosure were negative, and this positive shift felt alien to her. Feeling relieved evidenced the reality of being burdened for so long. Amy emphasises with other autistic survivors and she wants them to experience the support that she did within her interview.

### **Discussion: The mental connection is the most important**

This subordinate theme was poignant as I had not initially considered the importance of human connection. Lieberman (2013) states "our need to connect is as fundamental as our need for food and water" (no pagination). Human beings are wired to connect with others which can affect one's health (Martino, Pegg and Frates, 2015). Human connection fosters subjective well-being (Ruppel et al., 2022), and socially interacting is essential to human development (Martino, Pegg and Frates, 2015). Non-autistic people generally do not have difficulties with social interaction to the extent that is experienced by autistic individuals. The desire for autistic people to connect, yet the inability to do so is complex because the symptoms of autism can impede the connection process.

This theme elucidated that creative modes of connection are effective during the recovery process. It supports the bloggers who connected with each other whilst sharing their stories of SAV which helped their recovery process because they felt less isolated. Possibly, autistic people are more in tune with themselves than initially thought. This could be due to having to work at connection compared to non-autistic people. Unsurprisingly, the participants in this research had trust issues which could be a barrier to recovery. Healthy connections equate to trust which is essential whilst

building good relationships. Trust takes time, particularly for autistic people because of communication difficulties and delays in cognitive processing. As trust is essential for effective therapeutic interventions, the complexity for some autistic individuals lies within their inability to understand the intentions of others. Trust had frequently been broken for the participants, and this could reinforce a domino effect whereby one trusts a person and they either let you down or abuse you.

Interestingly, BDSM was a sexual preference for each participant and it heightened my curiosity. Although it did not emerge as a theme, it is worthy of attention because of its association with connection. I considered whether there was a link between autism, BDSM and mental health. I reviewed the literature but it was limited, albeit it is addressed within the grey literature. Despite the lack of research evidence there is a growth of information addressing BDSM due to the best-selling book *'Fifty Shades of Grey'*. It raised BDSM awareness capturing the attention of many people from around the world who were opposed to it. This sparked interest-initiated discourses on its practices via social media and blogs. The film *Fifty Shades of Grey* was released 2015; *Fifty Shades Darker* in 2017; and *Fifty Shades Freed* in 2018. BDSM was central to the story lines and it ignited an interest for some researchers and can be found in the academic literature (Dunkley and Brotto, 2018; Graham et al., 2016; Simula, 2021; Wuyts and Morrens, 2022).

Boucher (2018) recognises the increase of autistic individuals engaging in BDSM. I considered the principles of BDSM and it is logical that it may be a sexual preference for some autistic people and/or survivors of SAV. This is because it incorporates everything that was lacking for each participant in this research regarding their sexual safety. If practised correctly, trust and safety are embedded within the safety

guidelines of BDSM. Scenes are discussed between each partner before the interaction of role play, creating predictability for both partners. Boundaries are implemented at the outset of scenes and safe words are agreed which are used if either partner wants to stop, and possibly reclaim control. If the practitioners strictly stay within those parameters, they are able to perform sexual activities knowing that they are safe. The power dynamics between the practitioners are significant because they have a choice of identity which is consensual, but consent can be revoked at any time (Brown, Barker and Rahman, 2020). BDSM can be a powerful experience and the trust between the practitioners can forge a strong connection between each other:

Practising BDSM can be understood as a process of increasing expansion, creation and connection, in which desire is seen as something we lack or need but rather as a process of striving and self-enhancement. (Carlström, 2019, p. 1)

Thom demonstrated how erotic asphyxiation (which is BDSM orientated) helped him to mentally connect with his partner. It is important to note that this is dangerous behaviour and not recommended (Coluccia et al., 2016). The connection associated with BDSM led me to consider its therapeutic effects that may benefit autistic people and survivors of SAV experiencing disconnection. Carlström (2019) acknowledges that some studies indicate the psychological welfare for practitioners of BDSM opposed to pathologising discourses. There are spiritual, therapeutic and psychological benefits of BDSM (Barker, Iantaffi and Gupta, 2007; Beckmann, 2001; Sagarin, Lee and Klement, 2015; Taylor and Ussher, 2001). Pitagora (2017) concluded that by achieving subspace, the submissive partner could experience reduced physical and emotional stress. Sexual submission and/or masochism could be a mode to a meditative or relaxed state of mind focusing on the self, and the here and now (Labrecque et al., 2020). This concurs with the viewpoint of Pitagora (2017):

It is suggested that periodic absences from an awareness of self and the pressures associated with identity maintenance can provide relief in the form of a therapeutic reduction of stress. (p. 49)

The correlation between autism, BDSM and the physical and psychological connection made by autistic people regarding their mental health is interesting. Alas, there is a stigma attached to BDSM identity (Bezreh, Weinberg and Edgar, 2012). Autism and BDSM identity may pose a challenge regarding their intersecting identities which are also associated with stigma.

In addition to this theme, the impact of Covid-19 led me to consider the importance of human connection which had initially been taken for granted and a neglected subject until isolation was enforced worldwide. It restricted physical social interactions and threatened the need for socially connecting in an unprecedented way (Parent et al., 2021). Society was severely affected by the imposed restrictions on our daily lives. People were forced to disconnect from each other and adopt creative modes of connection. Disconnection had a prolific effect on individual's mental health, evidenced by the upsurge of mental health problems and high prevalence rates of anxiety and depression. Individuals who had an innate ability to connect with others enjoying the comradery of family, friendships and the workplace became isolated. The freedom of choice taken away highlighted the core values of families and friendships. The effects of social disconnection have been devastating for many people, and extreme isolation is damaging (Ruppel et al., 2022). Autistic people have faced those difficulties on a daily basis prior to Covid-19. Non-autistic individuals have recently had a flavour of these challenges and reconnecting within a fragmented society detrimentally affected their health and safety. Covid-19 is linked to distinct levels of

psychological distress which substantially met the threshold for clinical intervention for those who were affected (Xiong et al., 2020).

## 6. The importance of sex education for autistic people: The missing pieces?

**4.8 Table 6: Superordinate theme and related subordinate themes**

Subordinate theme	Daisy	Elijah	Thom	Gwen	Amy	Elsie
A lack of sex education	✓	✓	✓	✓	✓	✓
Social media and online dangers	✓	✓			✓	✓
What's missing?	✓	✓	✓	✓	✓	✓

### A lack of sex education

Four participants did not receive adequate SE. Amy said “no”, and Elijah received “zilch”.

I never got any education around sex: I came to university, I explored a fetish society where they was practicing BDSM in the students union. That for me is when I kinda learnt more about being safer when it comes to sex and what I like and not. (Elijah)

Whilst at university Elijah gained some education about safer sex and his sexual preferences. The realisation regarding what he was instinctively drawn to and experienced negatively became acceptable, and available to him.

...being in special educational needs, quality of education is much lower than mainstream school so I think there is discrimination. (Elijah)

Elijah concluded that special schools were discriminatory as the quality of education was not as good as maintained schools/academies which are not special schools. This

runs counter to the experiences of Daisy, Thom, Gwen and Elsie who attended mainstream schools because they were dissatisfied with their level of SE as they only learnt scientific aspects:

The sex ed that I got when I was in year six was basically just girls grew tits, grew a bit of hair and then your're gonna start your periods: In year eight we were talking about the biological sex and the science behind it. (Daisy)

[SE] ...not officially. ...had plenty in the playground [laugh]. It was an all boy's grammar school. We didn't talk about it: ...biology, chemistry, physics, RE, for the moral and ethical stuff: We watched Monty Python's The Meaning of Life that was as close to a sex ed film that we got: Monty Python [singing] *every sperm is sacred every sperm is great* erm yeah that was sex education. (Thom)

Thom was educated at a male student school for pupils with high academic abilities and sex was deemed taboo. He mocked his SE which he deemed laughable. He named a comedy film and sarcastically sang and emphasised the lyrics referring to it being the extent of his SE. It is unclear whether Thom learnt about sex from the 'playground' which is common for non-autistic people or whether he had sex there.

I literally only remember one sentence from the entire assembly because it was *awfully* put together. It didn't make any sense. He was telling us to make sure you put a condom on: The only other thing that I remember is the period talk in year six and the boys were asked to leave the room [laugh]: ...where are you guys going? That's not ok. We have to deal with bleeding what do you guys deal with? (Gwen)

Gwen's SE was meaningless and she did not understand it. She emphasised 'awfully' regarding its formulation. Similar to Thom, Gwen found her experience laughable. She believes in the equality of SE "teach boys girls SE, so teach them about periods".

Primary school they did that whole see through image of a penis and a vagina thing: ...it was crap sex education [laugh]. We had

no idea to know what was normal and natural and to rely on our parents to tell us that these sorts of things, it's not necessarily going to be reliable and happen and it causes more, issues for people and it creates that situation where people, er men and women can be vulnerable without actually needing to be, it's not necessary if you know what I mean... (Elsie)

Likewise, Elsie's SE was inadequate and she too felt it was laughable. She raises an important point regarding who is best suited to teach it. The lack of reliance and/or trust upon parents regarding the teaching of SE is questionable; particularly, when they are the perpetrators positioning the child as 'vulnerable'. As in Elsie's case, her step-parent was the abuser.

### **Discussion: A lack of sex education**

This subordinate theme highlighted the lack of literature regarding sexual knowledge for autistic individuals and their specific needs remaining unaddressed. This contrasts with current interventions that are primarily designed for non-autistic people (Ragaglia, Caputi and Bulgarelli, 2023). The participants in this research lacked SE which seems problematic universally. In the UK, SE is generally inaccessible for autistic individuals, and they are in jeopardy of it being ineffective due to challenges in facilitating lessons with students who have various needs (Bloor et al., 2022). Davies et al. (2022) recognise the contention faced by educators in Canadian schools as they lack appropriate training to effectively deliver SE for young autistic individuals. It is important to consider that if the participants had received suitable SE, they may not have been as susceptible to SAV. Research evidence expels the myth that autistic individuals do not want to engage in sexual activity, and they are interested in the same way as non-autistic people (Hartmann et al., 2019; Haynes, 2013; Sala et al.,

2019). They also experience both sexual desire and satisfaction (Solomon, Pantalone and Faja, 2019). However, autistic individuals may have conflicting messages because society perceives them as non-sexual; therefore, SE may help their understanding of sexual desire contributing to their sense of self (Davies et al., 2022). Due to outdated perceptions that autistic individuals are uninterested in intimacy, it is feasible to suggest that it contributed towards poor quality SE. This was unsurprising because in 2013, I completed my MEd highlighting the stark lack of SE for autistic people. This is parallel to the experiences of the participants within this research a decade later. It is important to note that ten years ago, the participants would have fallen into this category whereby SE was inadequate. Five participants in this research had not got an autism diagnosis whilst in secondary education. Amy was “sixteen” when she was diagnosed which would have been towards the end of secondary school. Their SE was unsuitable as it was not tailored to meet their needs. The requirements of SE need to be inclusive with a one-size-fits-all approach being inadequate (Davies et al., 2022).

Autistic individuals have considerably less sexual knowledge than non-autistic people (Joyal et al. 2021). This is discriminatory and supports Elijah’s viewpoint as he felt discriminated because of his specialist education. Appropriate SE is at the core of safeguarding autistic people and those supporting them. Arguably, SE is more important for vulnerable and marginalised individuals to aid their protection (Brown, Peña and Rankin, 2017; Terrence Higgins Trust, 2016). Knowledge and victimisation are related and it holds importance for clinical intervention (Brown-Lavoie, Vecili and Weiss, 2014).

## Social media and online dangers

Daisy and Elijah fell prey to social media and online dangers, and they were both exposed to two acts of SAV on separate occasions. Firstly:

...we met online. It wasn't like through Facebook, it was through a site which was very defined to our sexual preferences: BDSM: I was groomed by my teacher who got into a relationship with me when I was seventeen. I was in a relationship with him until I was nineteen erm... he raped me twice, emotionally abused me as well. (Daisy)

Secondly:

...I went to uni. I met up with a friend that I'd been speaking to for quite some time online. Unknown to me he was actually grooming me again, and I ended up going into a sex club with him and getting gang raped. (Daisy)

Referring to social media and online dangers Daisy explained:

You never know who's gonna be behind that screen and when you're young you don't know if you're speaking to a twenty-five-year-old, or fifty-year-old man. You *don't know* the implications of sexting... because... most people know that if you send a picture of your tits it's gonna get sent round the school, and you learn that out the hard way: You don't know what's gonna happen in adult life. If you send them pictures it can be sold to a pornographic site... If your boyfriend records you, and you don't want it, he could then sell it on and it could be online, and once it's online you've got no way of taking it back... and it's not touched upon anywhere... and it's *disgusting* really... (Daisy)

Daisy repeated and emphasised 'you don't know' regarding social media and the danger of being unaware of who you are talking to because of anonymity. It is feasible to suggest that Daisy is referencing her own experience 'learn that out the hard way'. She may have posted photographic images of herself which were used against her,

and later regretted it. Daisy emphasises 'disgusting' referring to the lack of education about social media and online dangers. Disgust is an emotional response, and Daisy possibly felt repulsed as she learnt online dangers by experience rather than education.

For Elijah, firstly:

...online. He said he wanted to try anal and I was like no. For me, that should've been a red flag that..... that he wasn't really respectful of that choice. (Elijah)

Secondly:

...it was just like gay Grindr. ...online dating site, and we were just messaging each other and then we just met up a few days after [raped]. (Elijah)

Elijah's experiences exemplify how technology influences an individual's susceptibility to SAV. Metaphorically 'red flag' symbolises the danger sign which he did not recognise. Elijah fell silent, and allowing him this space gave him processing time and he makes sense of his experience.

...sex education should be more of actual sex education, because otherwise, people are just going to constantly keep learning about it from online, and porn, and tv programmes and that is not what sex is about. So therefore, we are all going to be comparing ourselves to that and it's horrible. (Elsie)

Elsie too referred to the dangers of social media. She believes that SE should be just that, suggesting that if it is not definitive, people will view the internet as sex related issues are readily available. 'Horrible' indicates Elsie's disapproval of the comparisons

between real people and porn characters, and she advocates for SE to address real-life phenomenon.

### **Discussion: Social media and online dangers**

This subordinate theme highlights the influence and dangers of technology. Modern-day society is governed by social media which is a universal and influential force within socialisation, education and communication. Computer-mediated communication is innovative, progressing from being a tool used for that of an academic nature, to social media giving a voice to the voiceless (Olaniran and Williams, 2020). Although the online world can be beneficial concerning societal matters, it can be dangerous if safety guidelines are unadhered to. Autistic people are sexual beings and if they do not receive appropriate SE, they will seek it via social media and pornography sites (Haynes, 2013). This poses a risk because they can be unsafe and provide information that does not reflect true-life situations.

Autistic people and individuals with communication difficulties often use the internet as a mode of communication because it is easier than face-to-face interaction (MENCAP, 2015). This research exposed the extent of the dangers that online communication can have on an individual's sexual safety. This concurs with Daisy's viewpoint as she highlighted the dangers for young people who do not know who is behind the screen whilst online. Non-autistic people are not exempt from online danger but the risk may be intensified for individuals with LDs due to increased vulnerability; obsessions; social naivety; cyberbullying; online grooming; and inappropriate content (MENCAP, 2015).

## What's missing?

Each participant expressed what was missing within their SE:

I knew nothing about STIs until I was in year eleven... in this country at the minute people are getting sexually active younger and younger... (Daisy)

There was a short pause after Daisy acknowledged that she did not know about STIs until she was fifteen-sixteen years old. Evidently, she made a connection between young people engaging in sexual activity and their risk of STIs; therefore, SE should broach this subject earlier. Furthermore:

Consent. Absolutely nothing on consent. There's nothing on online dating anymore. We're in a society where Tinder is the best way to meet someone or Facebook, or other websites like eHarmony, max.com, and we have no internet safety on sexual relationships. We have no awareness of how bad sexual abuse is... We have no awareness of what relationship abuse is... All we have in schools for young people to learn about sex is the science of it and how to populate the country. *That's it, that's what happens.* (Daisy)

Daisy firmly expressed what was missing in SE programmes and she repeated 'consent'. She raised the lack of online safety guidelines which is concerning due to living in a technological society whereby dating sites are foremost in meeting someone. Daisy reflected upon being uneducated on 'sexual' and 'relationship abuse'. Subsequently, she commented on the scientific aspects of SE and she emphasised 'that's it, that's what happens'. Her tone of voice was assertive, and she seemed to have a realisation that the topic of CSA was missing for her.

One of my mates who turned out to be gay said what about anal sex, and went, we don't talk about that here... and then moved on... So, you've just discriminated a large section of our

population because they are gay and they have no education about it. (Daisy)

...how to have anal, oral would've been useful: Safe sex and use of condoms: Consent was probably the big one for me so if I... didn't wanna do summut, that's fine. (Elijah)

Daisy and Elijah deemed that anal SE was missing in SE, and Daisy gave prominence to this being discriminatory within the gay population. Education regarding consent was important to Elijah because he non-consensually engaged in sexual behaviour because he did not know that he should consent.

Relationships might've been useful... how to have them and what they should look like. (Thom)

During Thom's narrative he described the multiple times he engaged in unhealthy relationships. He reflected and concluded that recognising healthy relationships was missing for him.

Gwen acknowledged that "losing your virginity is a big thing" but "no one prepares girls the fact that it hurts". For some girls it may not be painful but because Gwen's virginity was taken away at six-years-old undoubtedly, it would have been extremely painful.

Consent. That's a huge deal: Consent is everything. Explain it to them in laymen's terms: Consent consent consent! If you drill it into kids when they're young you won't have any problems when they come to teenagers. If you teach a boy always ask, if you teach a girl you can say no, and if you teach a boy a girl can say no to you, and you just have to say ok. If you teach them that, you're not going to have so many people being like I was abused, I was sexually assaulted: Consent consent consent! That's the main thing for me I think, in sex ed. (Gwen)

Gwen numerously repeated 'consent' and the metaphor 'drill' symbolises that repetition is the best way forward in helping young people to learn and remember as they get older.

Gwen and Elsie had opposing viewpoints regarding the age of when SE should be delivered:

...puberty wise I think it should be at the end of primary school. Teach them about periods and teach them about the construction of their genitals. Teach them what they're for but don't go explicit. When they get into high school cus they're around twelve to thirteen then, they already know what sex is. (Gwen)

Not in primary school. I'd say when they reach sixteen which is the legal age that kids can have sex. (Elsie)

A lot of people think oh well, that's a really young age. Well kids are to grow up at some point. If you don't tell them when they are thirteen and someone sexually assaults them when they are fourteen, they are not going to understand about age: Teach them age, so that if a kid is like actually I've been doing it for a lot longer, at least you've put out the question of has anyone experienced this because it might be the trigger in that kids head to be like oh, wait, I have. How else are you supposed to know unless you ask? (Gwen)

Gwen is aware of the controversy surrounding the appropriate age of providing SE. She put forward a good argument for why she feels individuals should be taught at a young age, and this is because of her experience of rape aged six. If an underage person has been exposed to sex it could act as a 'trigger' and identify that it is wrong prompting them to disclose it.

I didn't know what was happening. I just didn't know. I just didn't know what the dangers of sex were and I didn't know if it was ok or not: There should be more information on consent and what people should do if they're in a situation where they are violated. (Amy)

The missing pieces for Amy were the sexual dangers as she repeated 'didn't know'. Her lack of knowledge regarding 'consent' impacted upon consensual issues because of not understanding what was happening to her whilst being raped. She deems that information on the aftermath of SAV would be beneficial as evidently, she was bewildered.

...how do men and women have sex. That was kind've a thing I didn't know at this stage. Like school doesn't prepare you: ...learn about you know what it's like to have sex. (Elsie)

Elsie's perception was similar to Elijah's as she wanted to know how to perform sexual intercourse. She also explains the SE that is missing to conform to modern-day society:

...there are two mummies, there are two daddies, there are mummies that are now daddies, and I think that just needs to be normalised, so that it may take a take a couple of normalised and reduced generations but, when it comes to high school, no-one is ever going to get bullied, for coming out as being gay. I got it *so bad* cus I found out that I was bisexual in high school, and I got it bad, and I was in a school that had no minorities we had *no* ethnicities at all. (Elsie)

Elsie highlighted the importance of diversity education which was missing for her. She deems that discrimination may have been minimised if it had been taught. Her repetition and emphasis of 'bad' highlights the severity of the bullying she experienced due to her sexuality. She advocates for adversity acceptance whilst referring to minorities. SE programmes are needed to provide a comprehensive range of topics including culture, sexual identity, and positive attitudes towards the diversities of young people to minimise discrimination.

## **Discussion: What's missing?**

This subordinate theme illuminated the importance of SE for the autism population to keep themselves safe, and to minimise and/or prevent SAV. It is a legal right for autistic individuals to receive SE to enable them to gain an understanding of safe and consensual sex (Bloor et al., 2022), but this was not the case for the participants in this research. They acknowledged the missing pieces and disturbingly, for Elijah and Amy it was SE itself. The participants identified topics that would have been conducive to their sexual safety comprising sexual orientation; intimacy and love; internet safety; sexual health; clear guidelines on consent; knowledge of SAV to recognise and disclose it; anal sex; oral sex; healthy and unhealthy relationships; how to have sex and what it feels like; and diversity. Fundamentally, Daisy said “why not teach people not to rape”.

The importance of SE must not be underestimated for the autistic and non-autistic populations. Essentially, it provides information for individuals to enable independence and to establish safe sex lives (Bloor et al., 2022). This research highlighted the complexities of SAV within the autism populace, and the participants recognised their susceptibility due to being autistic. My experiences of working with autistic individuals, parenting an autistic child, and previous research (Haynes, 2013) led me to consider important educational topics comprising sexual preferences; masturbation; orgasmic sensations; oral and anal sex; CSA; disclosure processes; and seeking appropriate support services. CSA studies are crucial to breaking the taboo to help survivors understand that talking about their experiences is salient, and the importance of education regarding normal reactions to abuse and accessing helpful resources

(Becker-Blease and Freyd, 2006). Similarly, Amy felt that she would have benefited from knowing what to do regarding support post-SAV.

Current SE interventions do not address the social, cognitive and emotional needs of autistic individuals, and failing to acquire psychosexual skills denies them of developmental opportunities (Ragaglia, Caputi and Bulgarelli, 2023). Specific autism characteristics need to be recognised whilst developing SE programmes, and the voice of autistic people is essential whilst guiding the understanding of healthy sexuality (Solomon, Pantalone and Faja, 2019). Similarly, Davies et al. (2022) recommend involving parents and autistic individuals whilst adapting SE, and the provision of support for educators.

Daisy was the only participant to identify as heterosexual, and it is important to consider the implications associated with gender diversity which were raised by Elsie, and its inclusivity within SE. Davaki et al. (2013) highlight the multiple and intersectional discrimination regarding gender and disability. There is a high prevalence of autistic people who are attracted to multiple genders (Byers et al., 2013). It is essential to consider the intersection of sexual orientation and gender identity regarding sexual health education. Utilising intersectionality brings attention to marginalised groups within the autism population including individuals of colour; women; LGBTQIA+ community; non-verbal individuals; and those dependent upon support (Mallipeddi and VanDaalen, 2021). Byers et al. (2013) state "...normalize attraction to both genders and empower individuals to adopt the sexual identity that best fits their self-concept" (p. 2625).

## CHAPTER 5

### CONCLUSIONS - LIMITATIONS AND IMPLICATIONS FOR POLICY, PRACTICE AND SUPPORT, AND FUTURE RESEARCH

#### 5.1 Introduction

The final chapter provides conclusions to this thesis “What are the implications of sexual abuse within the autism population?” The research questions are restated below:

1. How do autistic individuals make sense of their lived experiences of SAV?
2. How does being autistic increase sexual vulnerability?
3. What are the implications for policy, practice and support?

The participants in this research were the crux to informing the research questions, together with consideration of the published and grey literature. Emotion work theory informed the interpretation and sense making of the data. It afforded a nuanced understanding of the ‘thinking’ and ‘feeling’ of SAV which is often lacking in studies. This research is an in-depth exploration of SAV from a phenomenological perspective. It affords an original contribution to the field of autism accessing the first-hand voice of autistic survivors. A lack of autistic voices in research is concerning because it limits the evidence base regarding how they experience and process SAV. Primary data are lacking in complex studies and secondary and third-hand data are utilised which may not offer a true reflection of real-life situations. In contrast, this study utilises primary data. It adds to the originality because it is an accurate and reliable source as it comes directly from individuals themselves. It brings to life the ‘thinking’ and ‘feeling’ of SAV within the autism population which is missing in the published literature, and contributes towards bridging this gap in knowledge. It adds to the secondary and third-

hand data providing a deeper understanding of first-hand accounts of autistic individuals. Research addressing SAV is generally undertaken with disabled children which is not disability specific (Kenny, Crocco and Long, 2021), and excludes autistic people.

Some of the research findings were compatible with the existing literature. Additionally, some novel outcomes emerged pertinent to this work and worthy of future research. Although it is not comparative research, it draws out similarities and differences between autistic and non-autistic populations and has implications for the treatment of autistic individuals. The deep immersion with each participant allowed them to give a detailed narrative of their lived experiences of SAV which helped to answer research question 1: How do autistic individuals make sense of their lived experiences of SAV? I utilised IPA and its philosophical underpinnings are idiographic (Willig, 2008). The double hermeneutic cycle enabled me to understand the participants trying to make sense of their phenomenon (Smith and Osborn, 2007b). They described 'what' they had experienced and 'how' they were affected by their experiences live within the interview process. It was poignant because it was the first time that the participants had effectively made sense of their experiences, and it provided a richer analysis of the data giving greater justice to the participant "warts and all" (Smith and Osborn, 2007b, p. 54). This was demonstrated by Thom, Elsie and Elijah as they each had a 'light-bulb moment'. In Elsie's case, unintentionally "somethings leaked out" (Smith and Osborn, 2007b, p. 54) that had eluded her. Ultimately, she acknowledged that her step-dad had *raped* her, and as she tried to avoid the reality that her mum was aware, she conceded.

Obtaining primary data from the lived experiences of autistic survivors was crucial to identifying the implications of SAV within the autism population as previously discussed. This was useful in the interpretation of their data because it came directly from the participants, and helped to answer research question 2: How does being autistic increase sexuality vulnerability? As each participant narrated their experiences, they evidently made sense of their sexual vulnerability. They acknowledged that being autistic in itself and the symptoms associated to autism contributed to their susceptibility to SAV. Communication and social difficulties were key factors due to misunderstanding the intentions of others, and their desperation to be accepted into society. They were perceptive of their vulnerability due to experiencing addiction; mental health; conflict; controlling behaviour; lack of independence; co-dependency; and role reversals which detrimentally affected them. This is not exclusive to autistic people, and non-autistic individuals are exposed to similar situations but adding autism into the mix further compounds autistic vulnerability.

The superordinate theme 'The bleeding edge of autistic pain' demonstrated how the participants made sense of autism and its relationship with sexual vulnerability. It illuminated the psychological and physical impacts of the trauma experienced due to surviving SAV. This impacted upon their sexual vulnerability as they engaged in risky behaviours to numb their pain, or to relieve the numbness. The superordinate theme 'My dysfunctional family came at a cost' brought attention to the participants' vulnerability posed by their family which was unrecognised. This impacted upon their disclosure process, resulting in a cycle of SAV. Furthermore, their symptoms of autism were not recognised by family members. Consideration deserves to be given to

whether they may have been less sexually vulnerable if they had an autism diagnosis in childhood. The superordinate theme 'Autistic chameleon in a crowd' exposed the dangers of people-pleasing and adept masking. It compounded their sexual vulnerability as they disguised their authenticity and exposed themselves to dangerous situations due to the desire to be loved, and to conform to societal norms. The superordinate theme 'Rape culture: The reality beyond the myth' expelled the myth that rape culture does not exist, and it is highly prevalent in the autism population. Each participant fell prey to the subsets of rape culture, positioning them sexually vulnerable. The subordinate themes 'Loss of empowerment and control', 'Sexual objectification', and 'Blurred lines: This is Normal - Isn't it?' captured the essence of sexual vulnerability regarding being autistic and rendering them as easy prey. The superordinate theme 'Specialist support services: Where are they?' raised awareness of the lack of knowledge and appropriate skills of health care professionals whilst supporting autistic survivors of SAV. Disturbingly, in some cases, it increased the participants' self-harm and suicidal ideation due to retraumatisation. It is worth considering whether their sexual vulnerability may have been minimised if the healthcare professionals had been positioned to effectively meet their needs, and obtain the support required to aid the healing process. The superordinate theme 'The importance of sex education for autistic people: The missing pieces?' identified that shockingly, a lack of/or no suitable SE added to each of the participants' sexual vulnerability which they acknowledged. They took the actions of their perpetrators at face value and when they were told to do something, they did it without question which was possibly due to their literalism. The topic of consent was fundamental regarding their sexual safety requirements because in some cases, the participants were not aware that they could say no.

Fundamentally, autism impacted heavily on each of the participants' susceptibility to SAV. Echoing the grey literature, it seems that when the participants received their autism diagnosis, they set off on a journey of self-discovery and acknowledged their sexual vulnerability was associated with being autistic. Research question 3 is answered at a later point in this chapter. First, I discuss some limitations of the research.

## **5.2 Limitations**

This research is subject to several limitations. Firstly, the participants were sampled from a higher education background. This may not be representative of survivors who do not have the intellectual abilities to articulate their experiences. Secondly, each participant offered a 'snapshot' perspective of their phenomenon. Although this may be considered a limitation, the participants offered important contributions because their in-depth narratives gave a detailed and nuanced description of their experiences. Thirdly, this research comprised six participants which may be considered a small sample, but it is a meaningful sample size for an in-depth phenomenological exploration (Smith, Flowers and Larkin, 2009). Representing a smaller group cannot be generalised to the wider population but it was not intended to be generalisable. The intention was to gain a deeper perspective from the experiences of each participant which was achieved via an idiographic approach underpinned by IPA.

Fourthly, language is integral to IPA (Willig, 2013). The purpose is for participants to tell their stories. The inclusion criteria affirmed that they were able to communicate spoken language to provide a detailed narrative. This may be ineffective for individuals with poor communication. However, as previously discussed there may be creative

ways to support those facing difficulties enabling them to effectively express themselves. Strikingly, each participant articulated their narratives and gave a thick description of their experiences. It is worth considering that although autistic individuals may effectively express themselves, support may still be needed which was evidenced in this research. I asked each participant to tell me their story, but some had difficulties in starting their narrative. I asked if they wanted me to prompt them by asking questions. This was an effective mode of communication enabling them to ease into the interview. They felt comfortable with the process and their narratives flowed. Tuffour (2017) made an important point regarding whether participants and researchers had the required communication skills to effectively express their experiences. This could inhibit the research findings if there is miscommunication between autistic participants and non-autistic researchers. It could be limiting if researchers are unfamiliar with autism and how autistic individuals present their body language. Subtle cues could be missed into their feelings restricting the quality of the analysis. This was not the case in this research because each participant effectively told their story. However, I cannot be sure that they did not experience misinterpretations regarding my interaction with them.

Finally, a potential limitation is that I did not pursue analysis checking with the participants. However, at the end of the interviews each participant informed me that it had been a cathartic experience because it was the first time they had fully told their story. They thanked me for giving them the opportunity to participate, and hoped it would benefit other autistic survivors of SAV. Furthermore, non-withdrawal was a good indicator that they were satisfied with the process.

### **5.3 Implications for policy, practice and support**

The research findings answered research question 3: What are the implications for policy, practice and support? The superordinate theme 'Specialist support services: Where are they?' exposed the implications concerning a lack of specialist support services that were disjointed, and this immensely impacted on five of the participants. Their support was inadequate as the professionals lacked autism knowledge and the skills required to effectively support them resulting in retraumatisation. The superordinate theme 'The importance of sex education for autistic people: The missing pieces?' revealed that suitable SE is vital for the autism population to aid their sexual safety, particularly as autistic sexual vulnerability featured heavily within the research findings. These two superordinate themes have implications for policy, practice and support which is now discussed.

### **5.4 Implications for policy**

The findings from this research are relevant to different sectors including health care, the CJS, and education. This concurs with the WHO (2019) advocating for updated policies and guidelines within the aforementioned sectors to identify effective support and therapeutic interventions for autistic survivors. This research highlighted that the professional stakeholders in these sectors lacked understanding and awareness of SAV within the autism population. Therefore, I recommend that guidelines and training for staff providing personal care is key to recognising the signs of SAV and not misattributing them to the symptoms of autism. It is essential that policymakers and service providers take the necessary steps to provide sexual safety requirements for autistic individuals to aid their protection, and that training and guidance is informed

by first-hand experience from autistic individuals. Attention needs to be given to raising awareness within the diverse sectors to promote a better understanding of its effects, and to implement suitable strategies to minimise this crime. To measure violence, methodologies need to be strengthened for it to be tested cross-culturally (WHO, 2013). This research supports the WHO (2019) providing recommendations for generating policies and action plans to determine a broader framework for the mental health of autistic individuals and those with disabilities. The WHO (2019) focuses on the contribution of developing evidence for effective strategies in the assessments and treatment of autism and developmental problems.

Recommendations are put forward for education authorities to regularly up-date SE programmes, and for policymakers to consider the deep-rooted impact of technology and the diversities faced within a modern world. Everything is easier and faster to access which can expose individuals to danger. The autism population need protection from abuse and it is essential that policymakers are mindful of their safety requirements whilst implementing policies. Health care needs have been missing within policies and psychological abuse can result in ill health.

I have put forward several recommendations for policymakers pertinent to SE to aid the sexual health and safety of autistic individuals and the prevention of SAV. The findings from this research illuminate the importance of high-quality SE for autistic people which was missing for the participants in this research. Similarly, non-autistic people may receive poor SE but arguably, it is more important for autistic individuals due to autistic sexual vulnerability. It is important to reiterate that the participants in this research were undiagnosed whilst in education, and they acknowledged the inadequacy of the content of their SE and how it was presented. Thus, consideration

deserves to be given to undiagnosed autistic and neurodiverse populations whilst being educated within a mainstream environment. To circumvent this problem, policy and practice need to take account of undiagnosed neurodivergent students to aid inclusivity whilst providing SE. This will help to promote autonomous and healthy decisions regarding their sexual safety requirements. I recommend tailoring mainstream SE policies to capture the inclusiveness of a wide range of neurodivergent students within a modern-society. It is unnecessary to reinvent the wheel and basically, implementing reasonable adjustments to enable neurodivergent individuals to gain comprehensive education would suffice in meeting their unique learning styles. This may be achieved by putting into practice individual sessions or small groups, as well as differentiation and additional support (Autism Education Trust, 2025). Furthermore, this research identified a gap in the effectiveness of teaching SE as the participants felt that their educators lacked the knowledge and training skills to teach autistic and neurodivergent learners. Autism Education Trust (2025) advocate the use of helpful teaching approaches to enable successful SE comprising the use of diverse resources; visual explanations; character development; accurate language; declarative language; and distancing techniques.

The Department for Education (DfE, 2000) SE policies had not been updated for twenty-one years, and subsequently it incorporated topics conforming to modern-day society. The focus is to educate young people about healthy and unhealthy relationships and the effects it has on their mental health and self-respect. It addresses safety issues including sexual consent law; exploitation; abuse; grooming; coercion; harassment; rape; domestic abuse; forced marriage; honour-based violence; and female genitalia mutilation (FGM) (DfE, 2021). The NAS (2022) offer guidelines for parents/carers including the typical aspects of SE incorporating puberty;

public/private; menstruation; personal hygiene; and physical development. Other important topics include body image; relationships and sex; staying safe and appropriate/inappropriate behaviour; sexual health; masturbation; sensory differences; language; it's alright; behaviour diaries; social stories™; and comic strip conversations (NAS, 2022). In addition to the SE programmes provided by the NAS, there are other suitable programmes available online for the autistic populace. Speak to the Potential, Ability, and Resilience inside every Kid (SPARK, 2024) provides a service to autistic teenagers and young adults. The Organization for Autism Research (OAR, 2024) offers a resource called Sex Ed for Self-Advocates relating to sexuality education. It aims to meet the needs of autistic individuals and those supporting them. The programmes incorporate topics comprising the scientific aspects of SE in addition to dating; sexual orientation and gender identity; and online relationships and safety. It would be advantageous to expand on these programmes to promote open discourse on topics that may be perceived as stigmatising.

Although the content of evolving SE programmes incorporates topics pertinent to modern-day society, the participants in this research identified additional ones to aid the sexual safety of autistic individuals. From these research findings and my previous study (Haynes, 2013), I recommend that policymakers give much consideration to SE that considers further development of clear consensual guidelines. Although consent may be deemed a grey area, it is vital for it to be taught in a direct, uncomplicated manner for both the autistic and non-autistic populations. Understanding consent is vital for guiding individuals whilst making safe sexual decisions. Ultimately, teach people, *not to rape*. Furthermore, self-awareness; intimacy and love; sexual desire; mechanics of sex and what it feels like; orgasm; knowledge of SAV to recognise and disclose it; and the aspects of sexualisation are fundamental subjects to be

implemented into SE. Delivering it with sensitivity and consideration given to the processing and cognitive abilities of all students towards their learning needs is imperative. A direct but subtle approach to igniting the dangers of sex for young people is applicable to their awareness of appropriate and inappropriate sexual behaviour. If they are in the hands of sexual predators, an understanding of this may trigger alarm bells to make them think it is inappropriate, and hopefully give them the confidence to disclose it.

There are controversial viewpoints regarding the appropriate age of delivering SE. Upon reflection of these research findings and the literature review, it would be beneficial for SE to be introduced in primary school for the autistic and non-autistic populations. They experience puberty and develop sexually in the same way. It is important for prepubescent children to be aware in advance of bodily and emotional changes that will take place to prepare them for puberty. Particularly, as the onset of puberty may occur earlier in young people nowadays.

When delivering SE in a mainstream setting that may include neurodiverse pupils, it is fundamental that policymakers consider how programmes are delivered. Being sensitive and considering the processing and cognitive abilities of all students towards their learning needs would be conducive. Furthermore, it would be beneficial for policymakers to involve autistic individuals in the development of SE programmes to enable creative modes of learning suitable for meeting their unique learning styles. It would be advantageous to take counsel from those with the lived knowledge of autistic SAV. Factual information would be conducive in achieving suitable SE for autistic and neurodivergent individuals. This is in contrast to policymakers who may not have the required knowledge to implement best practice in this skilled piece of work.

## **5.5 Implications for practice and support**

The research findings identified implications for practice and support relevant to service provision and disclosure; good practice of therapeutic intervention for autistic survivors; autism diagnosis; mental health issues; and inclusive SE. Referring to service provision, this research highlighted the lack of service delivery available to meet the needs of autistic individuals, exposing fragmented services. This had implications for the disclosure process because it hindered the support required to disclose SAV. Carbajal and Praetorius (2020) acknowledge the many studies undertaken to understand autism but highlight the limited ones regarding how autism and SAV may have complications for treatment. To facilitate good practice there is a distinct need for suitable joined up services enabling a smooth pathway from disclosure to therapeutic intervention. There are implications for those who are unaware that they have been victimised. SAV cannot be disclosed if an individual does not recognise it as abuse and this was the case for Thom and Elsie. It is critical that interviewers are trained because individuals are more likely to disclose violence and subsequently feel supported (WHO, 2013). It is essential for family/carers, friends, educators, and professionals to have a good awareness of the signs of SAV so it is not misattributed to autism itself.

McPhail (2015) suggests that the guidance of good practice is directed by strong theories regarding empirical support and implications for intervention, treatment, service delivery, education and advocacy. Good practice also involves therapists recognising their own strengths and limitations. They should be able to acknowledge if they are the most suitable person supporting their client. It is important that

practitioners are knowledgeable about autism and whether a referral to a different therapist or agency is required (Marshall, 2014). Autistic individuals have characteristics differentiating them from non-autistic people, and it is crucial that health-care providers do not have misconceptions which is a barrier to effective support (WHO, 2019). Some professionals hold stigmatising views (Shefer et al., 2014) and if this is the case, therapeutic interventions would be doomed from the outset.

As autism is a hidden disability, it is worth considering that some professionals may have difficulty recognising it, particularly if their client is undiagnosed and/or does not disclose their diagnosis. Children with disabilities and non-verbal individuals may display unusual behavioural signs compared to those who are typically developing; therefore, it is important to understand their behaviour and not attribute it to the condition (Allnock, Miller and Baker, 2019). Non-verbal autistic individuals may be exposed to greater risk than those who are verbal. If they cannot speak it is deemed they will not tell, highlighting the significance of giving non-verbal individuals, a voice. Although they may not use spoken language, they are entitled to be heard and this can be achieved via creative modes of communication.

This research highlighted the implications associated with the disclosure process within service provision. The professionals lacked the skills to provide appropriate support, highlighting the significance of autism awareness and training. It is essential for those who meet with autistic people to allow for their individual support needs to be met. Failure to understand how they are affected by their symptoms can have disturbing implications for disclosure and recovery. More learning is required about CSA disclosures to strengthen the knowledge base helping professionals assist

individuals in making earlier disclosures (Alaggia, Collin-Vézina and Lateef, 2019). Identifying the needs of each individual and understanding their mode of communication is essential for positive therapeutic interventions. It is important that therapists effectively read the facial expressions and body language of autistic individuals. Understanding self-stimulatory behaviours gives insight into their feelings. Timely intervention is required to prevent deterioration of mental health and to avoid further abuse. The WHO (2013) recommend accessing post-rape support within seventy-two hours of the violation.

Regarding good practice of therapeutic intervention for autistic survivors, I considered why Elijah was the only participant to receive effective therapy, and there are several factors to evaluate. Consideration deserves to be given to his autism diagnosis as he was the only participant diagnosed at the time of being in receipt of support. Upon disclosure, he received timely support. As his mentor I guided him to appropriate support services specialising in SAV. His caseworker had basic knowledge regarding autism but he was keen to learn how to support autistic individuals. It was agreed between the three of us that I would attend Elijah's therapy sessions, but leave the room if Elijah wanted to discuss issues without my presence. It helped Elijah to build a trusting relationship with his caseworker. Additionally, I supported the caseworker and guided him through the initial sessions. I met with him on separate occasions giving him an insight into autism and how to treat Elijah. There were occasions when the caseworker acknowledged his uncertainties and I advised and supported him. Whilst asking Elijah how he was feeling, I explained that he had difficulties in effectively expressing emotions. It is worth considering the intensity of emotions for autistic individuals compared to non-autistic people whilst engaging with therapy, and the implications it has for effective treatment.

The caseworker was guided by Elijah regarding the amount of therapeutic sessions he had. This was central to the effectiveness of his treatment because it was at his pace and not the caseworker's. Elijah had weekly sessions and then he decreased support knowing that he could increase it again at any time. I reduced my input and once Elijah felt fully comfortable and trusting of his caseworker, I withdrew support on the understanding that it could be resumed if needed. Elijah's therapy took as long as he needed and it spanned over an eighteen-month period. This time length was vital in aiding his recovery and he was left with the skills enabling him to manage post-therapy. It is important to consider the length of sessions for autistic individuals generally, and block sessions of six to twenty weeks are likely to be ineffective. A leeway of time is recommended to build up trust with a survivor's therapist and to accommodate the possible delay in cognitive processing.

The process of Elijah's support upon disclosure is an effective model of therapeutic intervention. It is one to be considered whilst supporting autistic survivors to achieve positive recovery outcomes, and consistent collaboration between services is imperative. Also, relatively simple adaptations and multi-agency work can make therapy effective. It seems that standardised interventions designed for non-autistic people are ineffective and creative ways of therapy are beneficial for autistic people. In accordance with this good model of practice, NAS Respond (2024) provide a therapeutic service for autistic individuals and those with LDs who have been traumatised or endured SAV. It is a specialist service offering psychotherapy and advocacy. It can also be accessed by their parents/carers, family members, partner, professional, and/or volunteer. Long-term psychotherapy is available for a median time of two-three years. Respond offers creative modes of therapy comprising Psychodynamic; Gestalt; Play therapy; Art therapy; Drama therapy; and Dance

Movement therapy. This is a holistic therapeutic service provision which embraces those impacted by the ripple effects of SAV which are highlighted in these research findings.

The research evidence suggests that receiving an early autism diagnosis is imperative in accessing timely intervention and improved long-term outcomes (Okoye et al., 2023). It can significantly improve the quality of life for autistic individuals and their families/carers (Elder et al., 2017). It is beneficial to implement specialist interventions tailored to meet their specific needs (Okoye et al., 2023). However, there are still widespread challenges facing those in the process of receiving an autism assessment and diagnosis. These research findings highlighted the damaging effects caused to the participants in this research as they were diagnosed in adulthood. Considering the implications for practice and support, greater autism awareness and training remains paramount in recognising the symptoms of autism to aid individuals to access appropriate and timely provision. There has been an upsurge of autism diagnoses in females, and due to the high demand of referrals, improved waiting time is essential. Furthermore, support services are disjointed, and joined up pathways would be beneficial to avoid referrals to numerous professionals during the diagnostic process. This would help to alleviate distress caused to individuals whilst awaiting the assessment and diagnostic process.

This research exposed the severity of the mental health needs of each participant and the impact it had on their well-being. Depression, anxiety and OCD are commonly associated with autistic individuals and PTSD is predominantly overlooked (Gravitz, 2018). Moore, Larkin and Foley (2024) acknowledge that empirical research and current professional guidelines are fundamental in the modification of standard mental

health interventions to effectively meet the needs of autistic individuals. There is no literature available addressing the intersect of SAV, autism, mental health and PTSD prior to this research. This is concerning because as previously discussed Gravitz (2018) states that being autistic in itself can be traumatic, and this research supports those findings. As this population is susceptible to SAV, it is likely that they may someday encounter support services. Each participant in this research experienced numerous traumas in addition to multiple identities and experienced PTSD; in some cases, complex PTSD. It is vital to consider that they had not got an autism diagnosis at the time of therapeutic interventions. This possibly impeded the effectiveness of their support, highlighting that standardised approaches are unsuitable for autistic individuals.

The standardisation of approaches whilst supporting autistic individuals deserves consideration. This research has exposed that they are not particularly conducive in meeting the needs of the autism population, and tailored support would be more effective. Regarding SE, this research highlighted that standardised processes were unsuitable in meeting the needs of the participants. Tailoring it towards the cognitive learning abilities of autistic individuals to meet their unique learning requirements is recommended. This research highlighted a stark lack of SE for each participant. This concurs with the literature review suggesting that autistic people are frequently excluded from SE programmes which is discriminatory. Mandatory SE is vital with the inclusion of specific subjects being taught in addition to the scientific aspects. It would be valuable to include topics which are compatible with the diversities of modern-day society which were previously discussed in the implications for policy section. Those recommendations would aid the safety of vulnerable young people. It is important for

parents/carers and professionals to be educated about SE enabling consistency whilst discussing it. It is vital for autistic individuals to contribute towards developing SE programmes as opposed to being subjected to the ideas of professionals who might not have the appropriate knowledge to develop them effectively.

## **5.6 Implications for research**

There are several gaps in the literature worthy of future research including late autism diagnosis; implications for those who are unable to effectively express themselves; female perpetration and male-on-male abuse; dysfunctional family; capturing the experiences of SAV within the academic literature; and comparative studies. As previously discussed regarding late autism diagnosis, this research and the grey literature highlighted the implications of receiving a diagnosis in adulthood. It would be interesting for future researchers to examine whether autistic individuals would be less susceptible to SAV if they had an autism diagnosis in childhood. Consideration deserves to be given to the vulnerability of autistic individuals and the implications it has for sexual vulnerability. Possibly, an early diagnosis may help to minimise their sexual safety by implementing precautionary safety measures such as tailored SE to meet their needs.

Another research implication is the barriers for those who are unable to effectively express themselves creating collective challenges for future researchers; the CJS; support services; and therapeutic interventions whilst supporting autistic individuals. There is a gap in the research evidence with little or no attention given to this neglected area. Proposals for future research into the implications for autistic people with LDs and/or non-verbal victims of SAV are essential for their treatment and safety.

Furthermore, there are implications for research regarding how the CJS manage the barriers to reporting, investigating, prosecuting, and the sentencing of SAV (Wieberneit et al., 2024). Autistic and non-autistic survivors of SAV may face the aforementioned challenges; however, they could be intensified for autistic individuals. Attention needs to be given to the experiences of survivors of SAV whilst accessing the CJS to minimise additional distress that may be caused by being autistic. Future research into the CJSs management of disabled and marginalised groups would benefit diverse populations to enable their treatment needs to be met.

Concerning female perpetration and male-on-male abuse, there is a stark gap in the research evidence to be bridged as SAV is typically associated with male perpetrators. This research highlighted that women can be abusers, and there is an underrepresentation within the literature regarding sexual victimisation for those who experience female perpetration (Munroe and Shumway, 2020). This has implications for gender equality and bringing perpetrators to justice. As women cannot be prosecuted for rape within the UK legal system, it is an injustice for men who promote gender equality (Petitions UK Government and Parliament, 2020). Further research is required to explore female perpetration to break down the stigma of male victimisation by women. This research highlighted the taboo of male-on-male rape and the associated stigma preventing disclosure. Although this is not a new phenomenon, male victimisation is neglected within research. Greater emphasis has been given to female victimisation although male prevalence of SAV is circumstantially similar to that of women (Stemple and Meyer, 2014). There is an increased awareness in social media and television soaps addressing it, but there is a distinct need for additional understanding within the academic literature. Further research is essential as it has

implications for the disclosure process; treatment by the CJS; therapeutic interventions; mental health; and men's safety.

Referring to dysfunctional families, there is a gap in research regarding greater implications for autistic individuals compared to non-autistic people whilst living within a dysfunctional family, and their perception of healthy and unhealthy relationships. As far as I am aware, there is no literature in this area and it is essential that researchers examine how autistic people are psychologically affected. Furthermore, it is disturbing that there is no research evidence addressing autistic caregivers compared to the copious supply of literature regarding non-autistic caregivers.

The WHO (2013) recognise the lack of knowledge regarding how to capture the experiences of SAV. Although there does not appear to be any research evidence addressing this within the general population, this research accessed the first-hand voice of survivors of SAV which filled the gap in knowledge from the autism perspective. Incorporating the emotions of the participants and researcher contributed to the knowledge base by bringing to life the realities of 'thinking' and 'feeling' rape. This study supports Gibbs et al. (2021) acknowledging that further research is required to gain more insight into the scope and nature of violence of autistic individuals. It would be valuable for future researchers to expand on this research to add to the evidence base addressing the prevention of SAV, and to include autistic individuals to gain their perspective.

Finally, this was not comparative research but the experiences of SAV between autistic and non-autistic individuals is worthy of future research. A more systematic comparison between these groups would be beneficial to identify improved treatment

for autistic survivors of SAV to minimise the added challenges faced by being autistic. This study exposed that SAV is rife within the general population. In comparison, the prevalence rates are much greater within the autism populace. There is a synergy into the way SAV is inflicted upon both populations. It would be valuable to build upon the similarities and differences referenced within this study. Although this research highlighted the physical harm of SAV, it elucidated the long-term psychological damage that has been overlooked for autistic survivors. The psychological effects of SAV are well presented in the published literature but evidently, this research is the first to address them within the autistic population.

### **5.7 My concluding thoughts**

As I near the end of this thesis, I would like to add my concluding thoughts. Hopefully, future researchers will draw upon this research as there is a need for greater first-hand autistic accounts of SAV. It clarifies that autistic people can, and do, make valuable contributions to research if given the opportunity. Expanding this research would be beneficial to aid the protection of the autism population. Having the opportunity to complete complex research for vulnerable individuals has been awe-inspiring. Sharing my emotionality and personal experiences to enhance this study has not only been worthwhile but a cathartic experience. I encourage and applaud determined researchers to seize opportunities and take full advantage of undertaking complex research that will not only benefit others, but themselves.

As my PhD journey concludes, I recognise the distinct change in myself as a researcher, and I am a different person to who I was ten years ago whilst setting out en route. Through reflexivity, I effectively worked out my purpose in life. That is to

absorb and share knowledge to educate others, similarly to my participants who have educated me and informed the research evidence of a much-neglected phenomenon. I hope that I have offered an authentic interpretation of their narratives and given them the justice they truly deserve. Finally, I would like to end my thesis where I started and that is to dispel the myth associated with the ostrich:

An ostrich does not bury its head in the sand out of fear of the unknown, but to protect their eggs. To safeguard our children, humans need to take their head out of the sand and take a look at what is known, without fear. (Haynes, 2022)

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## **APPENDIX I**

### **STAKEHOLDER MEETINGS AND PILOT**

#### **Practicalities**

Consideration was given to the practical difficulties which could arise prior to undertaking the stakeholder meetings and pilot comprising time; costings; equipment; transport; data sources; and researcher aptitudes. Due to my research being self-funded, it allowed me the flexibility to adapt a research design that would be suitable to meet my needs as the researcher and those of the participants. I did not face any problems regarding practicalities as I had the time to fit in with the participants and I was able to travel to meet them at a convenient location of their choice.

#### **Conducting the stakeholder focus group and semi-structured interview**

Although a focus group and semi-structured interview are different in their methodology, they have a similar structure. A purposive sampling approach was undertaken as opposed to random sampling because the participants are atypical of the populace and may be deemed biased. The purpose is to gain in-depth understanding into phenomena which only those with specific knowledge have (Bluff, 2005).

I sent an advanced package of information to all participants recruited which included an introductory information sheet that provided a permanent record of the research (and adjusted accordingly for the semi-structured interview), and an informed consent

form. I conducted the focus group and semi-structured interview in a neutral location. I introduced each of them by clarifying my role and that of the participant. I explained the purpose of the interviews and the five questions to be explored within a thirty-minute duration. I discussed confidentiality and how the results would be utilised. I initiated interaction with the participants to build up a rapport and to put them at ease. It was made clear that their participation was entirely voluntary and that they could withdraw from the study at any time without reason. Also, they could decline answering any questions that they felt uncomfortable with. The participants consented to the interviews being audio-recorded and written notes were taken in the event that the recordings failed (Robson, 2011). I explained that the data would be kept securely and that only I would have access to it, and that it would be destroyed upon completion of the study in compliance with the UK's Data Protection Act (1998).

I generated discussion by asking questions which were intended to be as open as possible to elicit responses enabling a better understanding of the participants' attitudes. An outline of the interview was prepared beforehand. It provided a framework for the interview schedule and I had an agenda of themes to be explored. This was beneficial as it enabled me to probe for further details by drawing out individuals' opinions, and I was able to tease out a diverse range of meanings on the topic under discussion. Not all of the questions were designed ahead of time and the majority were created during the interview. Two-way communication was facilitated as the participants could also ask me questions if they desired. During the interviews I clarified the meanings of the participant's comments to avoid any misinterpretations (Kvale, 1996). I was aware of the use of body language from my role as the interviewer and that of the participant. I nodded occasionally and/or would say "mmm" which

suggested that the participant continue with dialogue. I also allowed for silence which gave the participants the opportunity to reflect. I concluded the two stakeholder meetings by asking if there were any additional comments that might be significant to the topic, and then thanked the participants for their participation.

### **Stakeholder focus group discussion**

All of the participants involved in the focus group were from the same institution. I contacted each individual via telephone and arranged a convenient meeting time and venue which suited all involved. Five participants were invited to participate; however, on the day of the interview one was unable to attend due to emergency work commitments. The participants included a specialist mental health mentor and counsellor; autism specialist; disability advisor and a welfare vice president for the student union. A round-table approach was utilised which involved going in one direction around the table. I believed that it would be advantageous as it would give the participants the opportunity to interact from the start of the interview, and to allow equal involvement within the group discussion. It enabled the participants to share an even position regarding their work responsibilities which can add to an exchange of opinions and experience without any difficulties associated with power differences (Robson, 2011).

At the outset of the focus group I clarified that all information disclosed would be confidential, and data collected would be anonymised in accordance with the Data Protection Act (1998) as the material would be sensitive. Upon completion of the interviews, I asked each participant to respect each other's comments and to not

discuss any contributions outside of the interview. The participants were asked to sign an individual confidentiality form in addition to the consent forms; however, I am not sure if confidentiality can be fully guaranteed within a focus group setting (Gibbs, 1997).

### **Stakeholder semi-structured interview**

The stakeholder participant for the semi-structured interview was an ISVA, and the intention was to gain in-depth knowledge into the phenomenon of SAV. The semi-structured interview was advantageous as it allowed me to ask questions which were not rigidly planned, and aided a natural flow to the conversation. I probed for further information to tease out a deeper response to the questions adding to the richness of the data (Boyce and Neale, 2006). It was in an atmosphere of trust, acceptance and mutual respect (Richardson, 2002).

### **Results of the stakeholder meetings**

A GT approach was utilised to analyse the data. GT is explicitly emergent and does not begin with a theory and then attempt to prove it, but it begins with an area of study and subsequently, what is relevant is allowed to emerge from the research. It is particularly valuable for exploring interactions and the behaviour of groups where there has been insignificant attention of related issues that affect individual's lives (Crooks, 2001). The stakeholder discussions accumulated a copious supply of data and the analysis was extremely time consuming. I completely immersed myself into the data by repeatedly listening to the audio-recordings, and I transcribed them verbatim. I became familiar with the information and the analysis was achieved by using memos,

coding, and constant comparison throughout the analytical procedure. Several common themes emerged which are listed below and then discussed in further detail:

1. High prevalence rate of sexual abuse and violence within the autism population
2. Revictimisation of survivors
3. Importance of advocacy
4. Creativity in supporting survivors
5. Signs of sexual abuse mistaken for those associated with autism.

### **1. High prevalence rate of sexual abuse within the autism population**

An unexpected theme to emerge was that three participants revealed that they had worked with “*numerous survivors of sexual abuse with a diagnosis of autism*” as well as the general population. All participants commented that there were significant differences whilst supporting autistic individuals due to the symptoms of autism comprising communication and social difficulties, sensory sensitivities and emotional processing. It was identified that the symptoms of autism can adversely impact upon disclosure and reporting SAV to the correct authorities.

### **2. Revictimisation of survivors**

An important theme that emerged was the revictimisation of survivors of SAV whilst disclosing and reporting it. The autism specialist described how she supported a survivor through the disclosure process. The victim retold her account to various professionals and she was disbelieved resulting in secondary rape. She explained that disbelief and the feelings of betrayal were more painful than the violation itself. She

retracted her disclosure and declined any support offered, and her coping mechanism was that she self-harmed. Concerningly, this was the general consensus of each participant who had been involved with similar cases. These findings concur with the literature review exposing the retraumatisation of victims who have disclosed to the authorities which overwhelmingly added to their suffering (Hayes et al., 2011; Hovath et al., 2014; Plotnikoff and Woolfson, 2009; Westcott and Page, 2002). All participants were disturbed by the fragmentation of support services resulting in the victim retelling their story to numerous people.

### **3. Importance of advocacy**

Another theme was the importance of having an advocate to support autistic individuals during the disclosure process. The disability advisor suggested that *“survivors of abuse would benefit from having an advocate with them whilst reporting to the police... it would be beneficial in guiding the police to get the correct response from the victim”*. The autism specialist agreed and explained *“the emotions displayed by a person with autism might be completely different to what you might expect... an advocate could assist the individual by helping them express their emotions and communicate on their behalf”*. This concurs with the NAS (2014) stating the necessity of an “appropriate adult” (p. 24) to help support the process, and recommend that the person has specialist understanding whilst supporting an individual with communication difficulties.

### **4. Creativity in supporting survivors**

This theme highlighted that each participant recognised the need for more creative ways of supporting survivors of SAV as opposed to the *“formal sit down and tell”* which

might not meet the needs of autistic individuals. The autism specialist commented *“writing or drawing can be a perfect model to assist people in effectively expressing their thoughts and emotions as it can be less intrusive”*. This concurs with the research evidence which highlights the benefits of creative modes of communication whilst supporting autistic individuals enabling them to effectively express themselves (Dewinter et al., 2017; King, Williams and Gleeson, 2017; Adams and Stephenson, 2016). The autism specialist also acknowledged that identifying with their special interests can be an effective way of working with an autistic individual. Although the current literature is beginning to recognise the need for specific guidelines concerning the most suitable ways of interviewing autistic individuals, there is still much work that needs to be done to create a model for best practice. This may also be relevant to the general population as both unsuitable and clumsy CSA interviewing techniques may negatively impact upon child survivors (Wood and Garven, 2000). Generally, people respond differently due to individual learning styles comprising visual, aural, verbal and kinaesthetic. They need to be considered for all survivors of SAV to effectively meet their needs whilst disclosing and reporting abuse.

##### **5. Signs of sexual abuse and violence mistaken for those associated with autism**

This theme was significant as it identified that the signs of SAV are frequently mistaken for those associated with autism. The specialist mental health mentor and counsellor stated *“it is vital for people supporting individuals with autism to have an awareness of sexual abuse in order to recognise the signs which can be manifested through mental health issues such as obsessive-compulsive disorder, post-traumatic stress disorder, pseudo-autism, self-harm”*. She suggested that SAV could go unnoticed if people were

unaware of the signs, thus negatively impacting upon their recovery. This concurs with the literature review which identified that sexually abused children may show this in ways that get ignored, or misattributed to autism as opposed to SAV (Edelson, 2010). If an autistic child has been sexually abused, there may be an increase in the intensity and frequency of symptoms associated with autism comprising self-stimulatory behaviours, self-injury, and stereotypical and repetitive behaviours to communicate SAV (Edelson, 2010). Also, it is important to identify psychological symptoms which may consist of acute anxiety, depression, PTSD, and not misattributing them to autism as it could impose additional harm (Edelson, 2010).

All participants identified with the paucity of information and limited models which influence the way professionals work with autistic survivors of SAV. The general consensus acknowledged that many professionals are not equipped with the knowledge, training or resources to carry out this skilled piece of work. They also suggested the need for joined up services and alternative creative ways of supporting autistic survivors.

### **Reflection of the stakeholder interviews**

Bolton (2010) believes that in order for responsible and ethical practice to take place, reflective and reflexive processes are a necessity. Upon reflection of the focus group and semi-structured interviews, I believe that there is not one particular research method that has greater suitability over the other, but employing overlapping similarities which echo a complementary use. The semi-structured interview was a powerful tool as it elucidated rich emotive data, and the focus group was valuable as

it generated relatively broad and nuanced information. Both methods led to similar results; therefore, a combination of both methodological approaches could achieve credible findings in effectively answering the research questions. Whilst undertaking two differing methods of data collection, I found the semi-structured interview less demanding than the focus group as I was able to concentrate all of my attention on one person. Whilst conducting the focus group, I observed that there were no power differences. However, this is not always the case as focus group methodology can be disadvantageous because group dynamics may change if there are power hierarchies (Robson, 2011).

I was aware of the importance of giving the participants an equal opportunity to voice their opinions, and to not allow any individual to dominate the group; therefore, a round-table approach was employed. Upon completion of the focus group, a participant disclosed that she felt uncomfortable when it came to her turn to speak because she felt pressured into doing so. Although I considered that a round-table approach would be inclusive, the participant disclosed that she would not have participated in the study had she known about this style of interviewing. Also, the other participants remarked that they wanted to make further comments but felt held back when it was not their turn. Although it is good practice not to pressurise participants to speak, it is also good practice to allow them the flexibility to have their say.

A professional from the focus group disclosed that her daughter had been the victim of rape, and as a mother she found it particularly emotionally challenging whilst supporting survivors of SAV. Furthermore, the participant within the semi-structured interview recalled her graphic experiences of CSA. She provided insight into her own

lived experience and spoke explicitly about intimate and taboo aspects of what she had endured. I was taken by surprise at the explicit personal disclosures of the professionals as I expected them to inform me about their professional perspectives. It was difficult not to emotionally react and to prevent my personal thoughts and feelings to interfere with the interviewing process. I felt that my own naivety and inexperience had been exposed and it was emotionally draining. This was pivotal as it highlighted the importance of preparing myself well to effectively interview vulnerable autistic individuals.

### **Influential factors of the semi-structured interview**

The data gathered from the ISVA during the semi-structured interview were poignant compared to data from the focus group as she spoke of her personal experiences of SAV. The data collected from the focus group were not as extreme but it was valuable as it offered a variety of professional opinions. The ISVA was a survivor of CSA and she openly discussed her experiences. Painful memories were resurfaced as she recalled her trauma. Her body language changed and she presented signs of anxiety and tension. This provoked a stark reminder of the ethical considerations whereby it is crucial to manage the risk of further harm for vulnerable participants. It also reinforced the importance of recognising non-verbal responses such as facial expressions and body language which might not be the case within an objectivist paradigm. This would be a key factor within the main study as autistic participants may find it difficult to express themselves verbally, and they may display unusual behaviours as a way of communicating. A fundamental part of the interview process is recognising and being responsive towards the participants' indicators of distress

and their emotional reactions. This can positively impact upon them disclosing additional data due to feeling understood (McCosker, 1995).

The individual interview was significant as the participant was an advocate for survivors of SAV. She agreed to give me feedback at the end of her interview regarding my interviewing technique. I welcomed her frank comments and I acted upon her advice. She recommended that it would be inappropriate to use the word 'interview' whilst approaching potential participants. Although this seems obvious now, I had failed to recognise the negative associations that could arise from the terminology. Subsequently, the interviews were referred to as a 'meeting' or 'discussion' to avoid any negative connotations. She suggested that when I consult with survivors of SAV, it would be helpful to adopt a more "*gentle*", "*softer*" approach. She explained that intonation can have differing meanings and that "**RAPE**" can sound very different to "*rape*". I listened again to the audio-recording which confirmed her comments. Evidently, I needed to reflect a softer tone within the forthcoming interviews as I sounded intimidating.

As I reflected upon her advice, I concluded that it would be beneficial to engage in training to enhance my knowledge of SAV. Subsequently, I attended seminars related to SAV; visited a SARC; networked with professionals working within the field of SAV; and I discussed the experiences of SAV with survivors from both the autistic and non-autistic populations.

## APPENDIX II

### PARTICIPANT INFORMATION SHEET

Researcher – Mrs Gaynor Haynes

Email: [REDACTED]

Mobile: [REDACTED]

### INFORMATION SHEET

**Study Title:** Implications associated with sexual abuse within the autism population?

#### **Invitation to take part**

I am a student at the University of Birmingham and I would like to invite you to take part in my research study that will contribute towards my Doctor of Philosophy (PhD). The study has been approved by the Ethics Research Committee at the University of Birmingham. Please read the following information carefully before you decide whether or not you would like to take part.

#### **What is the purpose of this study?**

To raise awareness of sexual abuse within the autism population and help to protect vulnerable people from future harm.

#### **Why have I been invited?**

You are 1 of 6 participants invited to take part in the study because of your experience of sexual abuse. The voice of autistic people is missing in the current literature and the information you provide will help to raise awareness of this under-researched topic.

#### **What do I have to do if I decide to take part?**

Your participation will consist of a minimum of 1 meeting and a maximum of 4 meetings and you will decide what suits you.

Meeting 1 – introduction to the researcher and getting to know each other

Meeting 2 – discussion meeting about your experience of sexual abuse

Meeting 3 – if you need more time a 3<sup>rd</sup> meeting will be offered

Meeting 4 – discuss/amend transcripts (optional) – end researcher/participant relationship

You might want to have an introductory meeting with the researcher and then decide that you want to tell the researcher about your experience of sexual abuse. One meeting might be enough but if you require longer there will be a maximum of 4 meetings altogether. However, the 4<sup>th</sup> meeting will be to discuss and amend the transcripts but this is optional - the researcher/participant relationship will end. If you do not want the 4<sup>th</sup> meeting the researcher/participant relationship will end beforehand

- We will meet at a time and place that is convenient for you
- A family member/friend/advocate/support worker or someone that you feel comfortable with can come along
- It will take approximately 2/3 hours - extra time will be allocated if needed

- I will ask you some questions about your experience of sexual abuse
- It will be audio-recorded and notes may be taken

**What questions will I be asked?**

The researcher will ask you questions which will be explicit, very personal and you may find them upsetting. There are no right or wrong answers and you will not be judged in any way. The interview can be stopped at any time if needed. You do not have to answer any questions that you feel uncomfortable with. The following questions are a guideline only:

- your story of sexual abuse
- how you were sexually abused
- who by
- for how long
- who did you tell about the abuse and why
- were you believed
- was it reported to the police
- were you supported after for the abuse
- what was helpful
- have you healed from the abuse

It may be difficult to tell your story but the researcher will help you by asking questions in a way that is easiest for you such as talking/drawing/writing or any other method that you feel comfortable with.

**What are the risks of taking part?**

- You may feel uncomfortable discussing your experience of sexual abuse
- You might remember unpleasant things that you had previously dealt with

An information package will be given to you at the end of the meeting with appropriate support networks if you are affected by taking part.

**What are the possible benefits of taking part?**

- You may not benefit directly by taking part in the study
- Your participation will be very important as it will help to increase the understanding of sexual abuse within society and the autism population

**Will my taking part be kept confidential?**

- Your taking part will be entirely confidential and only broken if you disclosed ongoing abuse; at risk of harm; if you were to harm another person
- All information collected in the study will be recorded and stored securely and anonymously for up to 10 years after data collection. You will have a participant identification code to ensure your identity will be anonymous
- Paper data will be stored in a locked cabinet and only the researcher will have access to the key
- Digital data will be stored on an encrypted memory stick

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

- A short document will be produced at the end of the study to inform you of the results and a full report will be available upon request
- Results of the study and quotes will be used in researchers PhD
- Results may be published or presented at professional meetings but anonymity will be maintained

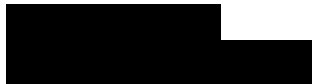
**Do I have to take part?**

- It is up to you to decide if you want to take part – it is entirely voluntary
- If you decide to take part and change your mind later, you will be able to withdraw your data up until 1 month after data collection without giving a good reason and no penalty incurred
- If you withdraw, your data will be destroyed

**What if there's a problem?**

You can contact the supervisors of the study if you have a complaint with how the research has been conducted:

Professor Julie Allan  
Head of School of Education



Dr Andrea Macleod  
Lecturer in Autism – School of Education



**What do I do now?**

If you are interested in taking part in the research or require further information please contact your service provider.

**APPENDIX III**

**PARTICIPANT CONSENT FORM**

**Study Title: What are the implications of sexual abuse within the autism population?**

Gaynor Haynes: PhD student at the University of Birmingham

**Participant Initials**

- 1. I confirm that I have read and understood the information sheet for the above study and have had the opportunity to ask questions
  
- 2. My participation in the study is voluntary. I am free to withdraw at any time up until 1 month after data collection without reasons
  
- 3. I agree to the meeting being audio-recorded
  
- 4. I agree to the use of anonymous quotes in the study, publications and professional meetings and I will not be identified
  
- 5. Researcher/participant relationship will end after a maximum of 4 meetings
  
- 6. I agree to take part in the above study

Name of participant .....

Signature .....

Date .....

Name of researcher .....

Signature .....

Date .....

**Thank you for completing this consent form. Please keep a copy for your record**

## APPENDIX IV

### INTERVIEW SCHEDULE AND QUESTIONS

The following is the interview schedule and questions, albeit the word 'interview' was not used with the participant as it could have a negative meaning and so I referred to it as a 'discussion' or 'meeting'. The research questions were grounded and positioned epistemologically in line with IPA (Smith, Flowers and Larkin, 2009). It is important to note that the interview schedule and questions were simply a guideline and the language on the agenda was not necessarily used within the interviews themselves.

#### ALLOW THE PARTICIPANT TO TELL THEIR STORY

##### **Section A. INTRODUCTION TO THE RESEARCH**

Develop and sustain rapport within the researcher/participant relationship.

##### **Section B. EXPERIENCE OF SEXUAL ABUSE**

**Question 1** – Can you tell me about your experience of sexual abuse? What happened?

###### *Prompts*

- When did it happen?
- Where did it happen?
- Who was the abuser?
- How were you targeted?

**Question 2** - Did you change in any way when you were being sexually abused?

###### *Prompts*

- If so, how?
- Why?
- Have the problems with sexual abuse changed the way you think or feel about yourself?
- Do you see yourself differently now than before you were abused? In what ways?

**Question 3** – What emotions did you experience?

###### *Prompt*

- Which was the predominant emotion that you felt?

**Question 4** - How did it affect the people closest to you such as your partner, family, friends, work colleagues?

##### **Section C. DISCLOSURE OF SEXUAL ABUSE**

**Question 1** - Tell me about your experience of disclosure?

###### *Prompts*

- Who did you disclose to? Why?

- How did they respond to your disclosure?
- How did you feel after disclosing?

#### **Section D. SUPPORT SERVICES**

**Question 1** - Were you aware of services available to you?

*Prompts*

- Did you access any support services?
- If so, how did they respond to your needs?

#### **Section E. RECOVERY**

**Question 1** – Do you feel that you've recovered from sexual abuse?

*Prompt*

- What coping strategies helped?

#### **Section F. IMPROVEMENTS**

**Question 1** - How could disclosure be made easier?

**Question 2** - How could reporting abuse be made easier?

**Question 3** - How could the criminal justice system be improved?

**Question 4** - How could support services be improved?

#### **Section G. FINALLY**

- I will thank participant for their time.
- Are there any questions you would like to ask me?
- A de-briefing will follow which will address a warning that they may experience

a delayed reaction to sharing sensitive information. Also, a user-friendly information package will be given to the participant with contact numbers to access further help, counselling services, and self-referrals will be provided.

## APPENDIX V

### ELSIE'S TRANSCRIPT

The following are the superordinate and subordinate themes that emerged from Elsie's transcript:

#### **Superordinate theme 1 and subordinate themes: The bleeding edge of autistic pain**

- I am so utterly vulnerable
- Coping mechanisms
- The dissociated-self

#### **Superordinate theme 2 and subordinate themes: My dysfunctional family came at a cost**

- My dysfunctional family and me
- All I need is love
- The ripple effects

#### **Superordinate theme 3 and subordinate themes: Autistic chameleon in a crowd**

- Identity issues: Who am I?
- People-pleaser
- Underneath the mask was the abuse
- But was it abuse? I never said no

#### **Superordinate theme 4 and subordinate themes: Rape culture: The reality beyond the myth**

- Loss of empowerment and control
- Sexual objectification
- Blurred lines: This is normal – isn't it?
- Victim-blaming

#### **Superordinate theme 5 and sub-ordinate themes: Specialist support services: Where are they?**

- Counselling isn't for me
- Retraumatization
- I don't understand my emotions: Do you?

## **Superordinate theme 6 and subordinate themes: The importance of sex education for autistic people: The missing pieces?**

- A lack of sex education
- Social media and online dangers
- What's missing?

Transcription code: EP6

*Elsie, I'm interested to know your story of sexual abuse, and I want to make this experience as comfortable as possible for you. You can either tell me your story or I can start to ask you questions if that would make it easier?*

Erm I will try and tell my story. I'm going to be jumping and starting timelines. I'll try my best to keep a flow because it's over a series of years. It's not easy to follow it, erm it was over erm eighteen months ago since I had to tell it to the police and spent the last eighteen months trying to forget it, so I'll do my best.

*That's fine, thank you.*

Erm want to go to the very beginning of meeting this guy. Erm my mum was a chronic alcoholic growing up through high school and primary school. Erm, she raised us alone. My dad left us er god when I was in year one, so when was that? Five or six years old so quite early, and mum she had one or two boyfriends growing up, but she never had anything you know particularly serious and then [sigh] I was in year seven or eight. I remember locations a lot more than dates and stuff cus it was in the [place name] the house bungalow sorry that she met this guy [Jacob]. Erm large guy, really fat. My mum wasn't exactly skinny herself but this guy took the biscuit. I mean wow erm and he was sweet and stuff at first. Yeah, he was sweet during those years when mum was dating him and I was one of those kids that was playing out in the street et cetera and that sort of stuff erm... Er they eventually got married, he moved in, they got married. Erm they seemed kind've ok together for a

while and then erm he got lazy. Erm my mum was already working near enough working fifty to sixty hours a week to try and do overtime and everything. Erm, she didn't really raise us as much as my grandparents, like, we'd finish school and we'd would go and stay at my grandparents until mum came to pick us up at ten o'clock, you know and that sort of thing. Erm she got ill, she got fibromyalgia. So erm Jacob then made her quit work, he wouldn't work himself. Erm, they had a market stall and it was just too much for her and he belittled her like, he reduced her self-value. My mum's a smart woman. She could've got to uni and everything. She attempted to do an open degree and failed but that was because of him telling her she was useless. So er we lost our house, our bungalow we were renting erm, because mum couldn't pay the rent. Erm but they weren't smart enough in this case. We er moved to [place name] now erm [place name] an expensive place. It's where [names] like to go shopping and they are always there. Erm and it is sort of a council estate, ex-council estate, but we went from renting a place that was five hundred a month to renting something seven hundred and fifty. I had my own room and we were great and we were there for six months and all of a sudden that started to go downhill. Erm [sigh] so that's just a bit of a back story of what they're like because now we lose the whole house, we go into temporary housing and that's when Jacob changed.

*So how did Jacob change?*

So erm [sigh] before he was like complimentary about my dresses I wore. I'd just sort of took it as like a dad saying his pride of his daughter being pretty that sort of thing, and with me I don't really hold people at a distance. I'm kind've all in so. If you're going to be my dad you are my dad, and everything that comes with it you, you will fulfil that role and you will hold that in my heart as well. So, in the temporary house

erm lots of stuff happened, so er I was seventeen by this point. Previously he'd done things like put me on his lap and had a hard on and stroking down your back.

*What age was that Elsie?*

Fifteen. That's sort of making me wonder was when I was fifteen. He met mum when I was in year eight so that's was when I twelve thirteen. So yeah fifteen was when it was, a little bit peculiar if you know what I mean. Erm mum even told me, mum even told me things that come to my head. Erm I don't wear night dresses or anything when I go to bed and mum must've suspected something because she started telling me, because as I got older I had to wear nightdresses so she must've suspected something. Erm and before I go any further, his history is he has abused a child before erm before before he met my mum. So, in my police case there was another girl involved historical, so he has done it before and my mum *knew* about it. Erm so yeah so, we get to the temporary flat which is on [place name] in [place name] so we'd gone from [place name] to [place name] to [place name]. Erm I'm seventeen by this point. I have a motorbike erm so I've got some independence. I'm in college erm and... starts [sigh] getting me drunk cus I'm starting the rebellious sort of side. I hadn't really done it through school always been following the rules, but he's encouraging me drinking Malibu which I can't drink anymore. but encouraging me drinking shots, and this is one memory of me being in, we're in the lounge in this place, and he's lined up *all* the shots and I can't remember how many there were but there were shot after shot after shot. Malibu was my *favourite* at the time. It makes me sick now if I smell it but *I loved it* erm... He carried me erm to bed ahead of my sister to the bedroom I shared with my sister and he got me undressed, completely undressed, and the reason I remember this is I'm pretty much a dress skirt kind've girl. Always have been but I was wearing jeans that day and the tugging is what

sticks in my memory. The drunk memory of it all but it's the tugging erm and then I feel that was then the trigger for things to... go downhill. Erm he kept accidentally coming into the room after I'd just had the shower. Erm errr even if it's not necessarily coming into the bathroom he would do it when I come into the bedroom. So, I've obviously got the towel around me, seeing me going into the bathroom and the bedroom and he comes in to tell me off for something that is stupid [sigh]. They trolled my money as well he did because I was getting EMA education maintenance allowance back in the day. Erm and I working as well. Erm they kept my money I was only allowed to ask them for my money if I wanted to go out because I had to get the bus to school sometimes [sigh].

*Can I ask you Elsie when you say they was that your mum and Jacob?*

Yeah, because mum erm used to ask me to buy the alcohol and stuff like that when I turned eighteen by that point but yeah. They kept they I wanna say it was they but cus I wanna feel like my mum just didn't let him do everything that she was had some level of control, but yeah [crying]. I am missing stuff at the moment but anyway erm my sister leaves. She accuses Jacob of being inappropriate to the police and they got the police involved and we had to go for an interview. Erm I at this point lied because I couldn't face telling the truth in this situation. Erm also my mum's dependent upon this man, she's in love with this man, she needed this man, and I even back then still made everyone happy. I would sacrifice my own needs, my own happiness for my sister, for my mum, even for Jacob because that was our family and it was up to me to keep us going, to keep us strong. That's how I felt erm I thought and felt that I was taking all of the inappropriate strokes, inappropriate touches, because he was groping me and stuff like that. Grabbing my arse when I walked out of the room erm always commenting on my breasts saying how they

were bigger and better than my mum's... Yeah, so I thought I had taken it to save my sister, as if in if he focuses his attention on me, he'll leave her alone. She's two years younger than me so she's sort, if I'm seventeen, she's fifteen, so she's starting to grow up you know... So as I've said yeah, I've kind've failed because I never talked to her so I don't the know the full ins and of what Gemma has said that Jacob has done to her, but from what the questions that the police were asking me, it was about inappropriate behaviour and touching and stuff and yeah.

*Can I clarify what you're saying to me please Elsie? When your sister went to the police regarding inappropriate touching was that about herself or about you?*

The police I don't think would've necessarily interviewed me because they were asking whether or not Jacob had been inappropriate with me as well as my sister, but I had assumed then that Gemma had gone saying that he had been like that with her... That was obviously back then so, er the police separated me and my sister from my mum that night. We went to go stay with our aunt and uncle. Gemma never came home after that. She stayed with my aunt and uncle, she never came back. I did two days later but what sticks to my mind so after we'd been to the police and had the interview and everything, I had not supported my sister in her accusations and lied. I can't face it but yeah. Erm I was getting my hair dyed that night. I was finally going to go from being blonde to black hair and because I was gothic, so it was finally I was getting it and I was having it done at [place name] which is the most expensive hairdressers in [place name]. Erm award winning hairdressers and erm the person who's doing it is now the managing director, is my aunt's aunt, so I was getting it cheap, and it's my moment, and I was like nothings ruining this for me. My mum turns up crying and begging me that it isn't true, and then begging me to keep him because she was going to lose him. If obviously it was but I was obviously in my

high. It's my I'm getting my hair dyed, I'm getting exactly what I want, getting it cut and its grown from long to short and everything, and I wasn't allowing anything to ruin that bubble. Like for *once* this is my moment but I still kept her happy didn't I. I still said no it's not true mum, Gemma is Gemma. You know what she's like and left it at that, and she had to go because she wasn't allowed to have any contact with us so she kinda broke the rules there. My aunty Karen wasn't there. She was the one we were staying with but yeah, I did go back after two days. Erm in hindsight I wish I hadn't erm because we finally left the temporary flat and got a flat on [place name] in [place name] and that's where he upped his game, *proper upped his game*. He then started asking things like do you masturbate? How do you masturbate? Are you using any toys? What do you do when you use these toys? I'm trying I can't lie very well... and I mean if the police had known known me back then, they would've known that was a case. I was fobbing this off but when you've known me I can't do it. It's, we were painting my room at the time, erm I'd always wanted white walls and black carpet and making it ready for me, we were painting my room at the time so [sigh] erm I tried to fob these questions off as best I can but didn't really do it. Erm later on mum, another time sorry, mum is either drunk or not there, I can't remember. She wasn't in the room but he decides to put porn on and I don't even know. It's like the first time I've actually sort of seen this and I don't know what to do or what. Do I let him know it's affecting me? It's hard because it's the first time I'm seeing something like that. I'm actually intrigued. I want to see it cus I want to know erm like how do men and women have sex. That was kind've a thing I didn't know at this stage. Like school doesn't prepare you for that kind of crap but I didn't want him to be around. Why did he put that on when I didn't know what what, and I froze. I didn't know what to do. I just sat there. I was seventeen or eighteen because I was in this

flat when I'd had my eighteenth birthday and I can't remember if it was before or after... erm... This is when I met Julian around that time. We started actually dating erm back in the temporary flat. We had our first date when we were up there. Erm our first anniversary was in [place name] so it was quite a nice surprise because Julian said go downstairs there's a box for you and there was a rose. He'd actually ordered a rose and had it delivered and it was really cute. So, I had an actual relationship to focus on through the dark because it was obviously the first year of me and Julian dating. He was so attentive, so romantic, so I couldn't believe it [laugh] you know.

*Was Julian your first boyfriend?*

Erm unless you count primary school you know, little boyfriends and stuff like that. Erm he was my first boyfriend boyfriend do you know what I mean, erm that I'd had in high school like boys that I'd er dated you know, hold hands with and crap like that you know and that sort of thing, but no Julian was my very first and I was his as well, so that was nice the two of us. I want to say cus although he was a virgin with me, I lied to him at first and said I was virgin with him, but I wasn't. Jacob had already taken that. Erm it was quite some time before I could actually tell the truth to Julian that you're the one that counts. In my eyes you are the one that counts but not the actual official one so yeah [sigh]... I don't know how to get to the next bit because erm beforehand it was just being inappropriate and weird and everything. Then we erm we get the opportunity to have sex. We had the upstairs flat and we get the opportunity to have the downstairs which are two levels sort of flat. It was a basement and ground floor erm... Gemma hadn't moved back by this point. She's still living with my aunt and uncle so erm it wasn't until I'd gone to uni for a year and came back that Gemma moved back with my mum, so she'd literally stayed away

erm... So I had this bed from the house in [place name] from erm me and my sister used to have bunkbeds but then when I got old enough I had my own bed and it was my black bed. Even back when I was in primary school I was still gothic, I had to share a room with a kid with purple and turquoise walls but so this was my bed that had moved with me *in every house we'd ever been in* except we get to this one downstairs and then what happens on that bed *I never wanted to see it ever again, I'd had this bed for a long time*. About ten to twelve years I'd had this bed and it was mine. You know I could put this bed together myself because it was very easy to put together. I was going to take it with me to uni and everything but no no [sigh]... can I jump the story a sec?

*Yes of course.*

Cus I'm kind've avoiding the last bit anyway erm... I do get the courage to leave. It's this bed was the final straw ok. So not only what Jacob did to me on that bed, it was I went to go stay with my nan for a day erm, when I came back Jacob's *sleazy brother* was sleeping on my bed, and that was the trigger that went no no no. Just sort of seeing that bed, seeing that man in it who was *gross* as well and just feeling I could not go back to that room. I left, finally left. I said to nan I'm I'm leaving, I'm not going back to mum. I didn't tell her the reason fully why I'm leaving and all of that but I said I said I'm doing it and I only had maybe a few months until I was going off to uni anyway. So, I was not going back and then my mum leaves him two weeks later. She proper leaves him and that was kinda good, *real good*. She did have to have an erm suicide attempt though. She took she's on fibromyalgia so she has gabapentin and some serious painkillers. She has morphine as well and being the alcoholic, she is she said she overdosed on I don't know how much gabapentin and morphine *with* a bottle of vodka. We found her by the seaside cus [name place] is by the sea. We

sectioned her cus she couldn't mentally cope with everything that's going on, but seeing that man at the hospital, holding on to her hand and her wanting to hold him, and need, him *really angered me*, and I mean *really angered me*. It's like we've left you, *how dare you* do this to me and my mother right now... I'd already had a suicide attempt myself earlier on in life. I'd erm cus at one point we'd actually gone to live at my nan's house that was... between [name place] and temporary sorry we'd stayed temporary with my nan and then erm... yeah, I made a suicide attempt over a boy, took as many paracetamols as there was in the house and all of that and I had my stomach pumped. Didn't put me off it though that still happened. So, I've been there with my mum, so I was sympathising with her and it was like we can do this together. You're now finally in my court you know, but no she still had to have a dependency upon him. Erm being my nan and my mum we were erm mum's next of kin, so we were the ones who were able to control erm her visiting rights, and when she was sectioned in the hospital erm and we banned him from seeing her. Erm so under no circumstances can that man go in there. Later on, only a couple of years back, mum did tell me that Jacob had raped her as well cus when I'd divulged what had happened to me, to my mum, she she cried and everything and she told me that he had done it to her too. Erm and that was a kinda because even in relationships even if you're a married couple it can still happen, and it just changed my viewpoint on like it's well if you're married then that means it's always consensual but it's not so it changed my mind then... Do you have any questions before I go any further?

*No. Not unless you want me to ask you some questions?*

Maybe it's because I'm trying to avoid a certain section [laugh].

My next question would be, what happened on that bed?

[Sigh] Ok I have a really high ceiling in that bedroom [sigh] erm... remember I mentioned he's really big, he's heavy... and I had a struggle when Julian when he was really heavy. I couldn't have him on top of me or anything. It's just horrible. Kept bringing back horrible memories and yes Julian's now lost a lot of weight, I still struggle cus Julian drops his weight down when when he's going for it, doesn't hold himself up. He hasn't got any upper strength and I feel like I'm being crushed and that that's same memory and feeling comes back to when Jacob's on top. When Jacob's on top of me even though the man was trying to hold his weight, he's just too big. You know what he's crushing me.

*Take your time Elsie. Let me know if you need to take a break.*

Do you want me tell to you what was went down exactly on the bed?

*If you can.*

I mean, I pretty much I'm sure you can gather he raped me on that bed and this is the thing it didn't just happen once, over and over again... and it's taken me a long time to realise that you don't have to say the words *no* for it to mean that consent wasn't given. Just because I was silent, staring at that ceiling that is *really high* and *vaulted*... I *can't* go into erm loft apartments, you know when they've got the ceilings like that cus it it it triggers. It's like one of those, like feeling like you know what I mean *I can't say the words very well*... Because of what I've been through, I want to help other people. You see I could've helped more people. I feel like it wasn't only really only until erm I had my breakdown in 2016 when my sister had told me, cus she was angry that the family wasn't happy with her, and that they never liked her and they always treated me over her and said it was because someone had known that something had happened between Jacob. Like I never told anyone specifically what happened but I implied you know what Gemma said about the police, it was

true you know [sigh], and she says and I said but I saved you Gemma. I saved you cus this was Christmas and she said but you didn't Elsie, and oh my god did that break me [crying] and then I couldn't handle any kind of stress anything in life. Er work got really hard because I... I'm sorry [crying].

*You don't need to apologise Elsie. Take your time.*

That's the bit that always get me cus I went through uni, I did everything, I grew up as an adult I survived because I thought I had saved my sister [crying]... and her telling that to me just meant I had to, I had to feel to remember and feel everything all over again, and it then it took me till the January to actually go to the police cus I started telling the family step by step. Erm my aunt who lives in [place name] who I'm close with, I told her first and she's begging me to go to the police... [crying]. But until that time with the police, I had not actually said to anybody, nobody, not even Jacob that... I still struggle saying these words... that *I was raped*... [sigh]... I told my dad as well eventually and and my dad's ex-army, and he's suffering at the moment quite badly at the moment with PTSD. Er and he couldn't handle it. Erm I told my dad when I didn't have exactly a great relationship, he was a distant man. He was always putting his step-children and my half-sister before me and anyone else [sigh]. But erm he tracked Jacob down like only a man in the army could and threatened him cus dad has a hunting cross-bow. Although he hasn't got a gun anymore he has a hunting cross-bow, and its lethal and he threatened Jacob. Jacob er got the police on my dad and my mum, and the police although my mum and my dad they kept this from me until I myself went to the police. They said that they weren't going to press charges to the police because erm although Jacob wanted to, they said that he doesn't have anything to stand on. Although mum and dad, dad had threatened to kill Jacob they said that the reason for it is that Jacob is not going

to want them to push this because otherwise it's going to go back on him, but it also said they can't do anything yet until I start. They tried to open a case based upon my mum saying that she had been raped by Jacob, and they said that she's not strong enough. There needs to be more evidence, they're not actually going to get a strong enough case. They can't reopen my sister's one because that was found erm innocent or what have you. They can't be recharged with the same offence or crime or something, and Gemma couldn't bring up anything new. So erm they're just waiting and apparently the police in [place name] had this little file waiting for me to come in and go through it. So yeah it was the January was when it started, got the police going and opened that can of worms and went through it and... told the story so bad [sigh]... I just lied there. I... I couldn't say anything [sigh]. I didn't trust my mum, she wanted this man, she needed this man, *he was a loser to me*... Four times... that's how many times it happened... and it was always in that room he erm which was the downstairs flat er in [place name], the one which is the basement and erm the upstairs bit.

*Was it four times that night?*

No. Four times over a few months.

*How old were you then Elsie?*

I'd had my eighteenth birthday so no I was seventeen the first time. Erm and then eighteen from then on... In my head or the way I see it is he had started grooming, started preparing from when I was fifteen and taking little steps like wearing me down, making me feel like it was normal you know, and it's ok. It's what he does or it's normalised me to that kind of behaviour... I always erm so outside in school cus I was still in sixth form in college and stuff so I always presented myself as being strong. I mean yeah, I didn't really have friends. I had people I knew that maybe one

one friend that I'd actually spend time with and et cetera, and yes all of these acquaintances I would do anything for them. I used to drive people around because I could drive then and erm I would buy people er coffees and drinks. Er this one had a birthday I went all out and getting presents and things. Like I was really really trying to be liked by people and not, and yes, stand out but not stand out for the wrong reason. I'd gone through that whole bullying stuff and being unusual, and not quite fitting in, and not understanding why either. Like it's just I don't know how to describe it it was a case of like I'm normal but, you're not normal if you know what I mean. I'm the normal one you guys aren't normal that's how I kind've felt. So erm yeah just wanted to be liked and continued this all through uni and work, and I'm a people pleaser, well and truly... I'm jumping again but erm... because of how my mum was complacent and letting it happen. Er she was always around you know what I mean. She was either drunk or just not paying attention. Not not wanting to see anything unusual. I love my mum but I can't have a relationship with her completely anymore. Even at uni she was always asking me for money. I got a bursary and she asked me for my bursary. Erm because obviously she didn't have a man anymore and so she couldn't really afford to do things anymore... They'd erm you know like provident loans those things, they'd taken one out in my name, and when I finished uni I'd found out because they'd turned up at my nan's house cus that's where I had my bank accounts linked to my nan's house still in [place name]. It's like when I come into my halls and uni, it's like there's no point so I still had banks linked to my nan's house, and provident had tracked me down to my nan's house. Thankfully it was erm when I was off uni and I was at my mum's flat at the time before my sister moved in, and it was it was still a grand that was left on that loan, because it had so much interest and months of them not paying, and so yeah I had to pay that because they

were at my nan's house and everything, and it was like, that was it. That's what I had left over, which was the summer student loan. When you get that yes, I'm going back home to [name place] so I didn't have any student halls to pay for, so I did have that money but I was going to save that cus I still had third year to go. Erm but I had to give it back to them, give it back to the provident loan. I still haven't had that money back from my mum.

*So, you were sexually abused and also financially abused?*

Yeah. I don't know what the loan was on. I haven't, mum can't remember. Mum had loads of provident loans and she can't remember what it was on, what that particular one was for. So, it was taken out in my name, that was horrible. She'd done a pretty damn good job of my signature as well to be perfectly fair [laugh] and the fact that the guy let her. Cus one of those few people he had to come round round every week to collect the money from you. The fact he'd let them do that, that was another bit... I'd bought them a car as well cus it was with the intention that it was going to be my car and so I had a Nationwide smart account sort of thing where I'd had investments and savings and that matured when I was seventeen. I was one of those weird kids and they needed a car, and I was like well I'm going to get a car soon cus I'm starting to learn to drive. It's going to be a while but I'll buy it now. You guys can use it and then I'll have it when I go off to uni and stuff. They wrecked this car and I mean wrecked it to the point where there were flies, maggots, all growing up the carpet cus it was water logged. I bought a beautiful car, it was a Peugeot 106. Yeah it was a kind've an oldish car at the time *but* it had been owned by this couple and it had only twenty-five thousand miles on the clock. They never left [place name] they'd only ever driven it from sort of I think it was from [place name] near [place name] to [place name] and back to do their shopping, and sort of like their little

travels around and it was very well looked after. It was serviced every year regardless of its mileage. It was a sound car and it was my first big purchase. I only paid five hundred and fifty quid though so that was very cheap. I was so happy, I loved it... [sigh] yeah [laugh]. I don't give my mum money anymore and er she still doesn't till this day and you know when you go to the pub she doesn't really buy me a drink. I still buy my own drink. She paid for me cus it was my sister's hen party a couple of weeks ago, sorry last weekend, sorry erm she actually paid for my meal then so that was good. She was like going to pay for my sisters and she was also saying I'll pay for yours as well Elsie, and it's ok, good, but she's not buying my drink. I only had a coke soo [laugh] small wins [laugh] losses as well.

*How did your mum react when you told her that you'd been raped?*

She was devastated. What triggered me to tell her was my sister was turning eighteen, no... I think it was her twenty-first or her eighteenth... I think it was her twenty-first to be honest. Actually, erm we were going to an Indian in [place name]. It was a crap Indian. Do not go to [place name]. It's it's so rubbish [laugh]. I've been spoilt by this place erm and Gemma had wanted to invite one of Jacob's nephews. Now when you see, when he he was my step-dad, he was my dad including his sisters, his cousins. They were my cousins, they were my family, except... what's his name Antony, he's my age although a year younger but still my age. *He's just like his uncle* erm... he had this way of making me feel like I'm special, and bearing in mind this is [name place] so the idea of like kissing cousins thing is normal for [name place]. But we're not actually cousins, but he had this way of making me feel good. Like he would smile at me and I I would actually kind've go whooa you know... He would start asking me if he could erm what's the word like erm take me out, like er just us you know. Do you want to come up to my room and we'll play a game

because I I was very heavily into my console gaming and stuff like that, but I was like I still kept it as a cousin? Am I right, you aren't my cousin. Erm he's got two little sisters that are about the same age as my little sister and younger, and they were like my little cousins you know erm... The first time he touched me I was playing on the games console, and he had never even sort of held my hand or anything, and I thought he was just being like a cousin you know. Like he actually really liked me you know, and its someone I can get on with unlike the rest of my family. I can actually get on with this guy you know. But he started, it was sort of like little strokes here and that sort of thing and already by this point I'd been conditioned that that kind of touch between families was ok, that it was normal, didn't feel normal, but it's ok, we're family, but it's not supposed to be. It was hard, going on going on in my head. I focused on my character a lot then, focused on my game erm... Although I stopped him then erm I said oh no I don't like that, don't touch me there. I kind've fobbed it off you know because I'm playing a game, enjoying my game, but I don't want to upset him because he's nice to me. I must keep him happy still. Like keep smiling at him and erm giving him what he wants and such, and the attention, like you are very good on this game and all this sort of thing, like ways that I can please someone as best I could. He then got slightly more... Started really going for my boobs erm... *He was persistent...* So, although I'm not going to say no, I'd sort of do the whole *Antony*, but I will also convince myself he's not my cousin, he's not my real cousin, and he likes you, he's nice, it's fine, but this is before Julian as well. I hadn't started dating Julian then erm and we were round their house a lot, erm blocked out Jacob's sisters name, Isabelle, sorry. Erm we were round their house a lot because Jacob's grandparent's live next door, so it was like go and see the two you know, and the kids were so much fun to play with as well. They had a field right at the back.

It was great. Like I just enjoyed going there. Started dreading going there though because it'd be like, oh is Antony going to be home. He is *ok*. I was staying at Jacob's parents instead but going over I started to avoid cus he was getting, I felt like I, he was convincing me that it's ok. We are not cousins and you are very beautiful and it's ok. I struggled with the idea of saying *no* because this is what he wants isn't it erm, I just have to make him happy, but yet it's not making me happy, but yeah it was it was horrible, so I started avoiding going around there. Erm it got noticed cus I was bored. Why aren't you round at Isabelle's? You know with the kids and yeah, so I had to keep going back erm... He did go as far as what's the word, er puts his fingers down my knickers what's the word that's associated with it? Fingered. That's the word yeah. Erm... I couldn't understand why I couldn't stop this very much. Like because I couldn't physically fight him off does that mean I was consenting to him doing that, it's confusing really. Like I didn't understand at the time what it meant. It was an unusual weird sensation and, but then Antony's nice to you, he likes you, so it's ok, but it's not. It was hard for me to understand it, you know what I mean, erm... I er stopped going around and I made every excuse I could to not, to not to go over because it was was wrong, and it felt wrong. I I couldn't say no, no matter what I couldn't say no, and I would see his face and I would get and now now I know it as anxiety that tightness in my chest sort of fear but not quite fear you know, and that would be as we were going down that street and I feel that level of anxiety. Erm so it's a a road towards into [place name] and my sister now lives on that exact same road, thankfully five miles apart. Scared that she's so close to it anyway. I I get the same level of anxiety going down that road just because it's the memory of going going there. Erm and obviously I I can't say anything at this point. I can't say that er Antony's doing these things because that means I didn't stop him, so therefore I

agreed to it, I'm part of it, I'm complacent in the act I am... I'm one half of a whole, I don't know. Er so the reason I told you this is because Gemma's twenty-first, she started contacting Antony on er er Facebook, and they were being friends. The guys grown-up now. He had a kid and all this sort of stuff and she wants to invite him to her twenty-first, and I straight away shot that down and I was like no. But I couldn't say to Gemma, no I said to mum, no don't. I can't I can't have him there and she pried and was like, it's because its Jacob's nephew and I had to tell her, and then I told her and she was angry. So, I didn't tell her about Antony. In fact, nobody knows about Antony. I'm not involving him with the police. I don't want him to come into anything. I I don't want him to turn around and say that erm I was consensual and everything, I was, a slut you know, and that I was to be used and I didn't want that kind of thing because although he is Jacob's nephew, he is nothing to do with me, and Jacob's blood nephew is Isabelle's adopted sister so it's still a level of separation. Thank god it was. I wanted that separate if you know what I mean.

*How old was you when he did that to you?*

Oh, this was when erm so mum and Jacob had been married about a year, so this would be around sixteen, fifteen sixteen, so yeah sixteen or so. So obviously I'm at that age, that's you know legally yes, a year younger than me, so there is that, although I never touched him. I would refuse because he would ask me to erm touch his penis and below him you know. No, I said no to that. I couldn't do that because yes that's not giving him what he wanted, but that was a level I wasn't prepared to go through because it's just no, but yeah, I suppose I'd allowed him to have that level with me, yeah. Any questions?

*So, am I right in saying that Jacob started touching you inappropriately from the age of about fifteen?*

Yeah cus he met my mum when I was in erm year eight which was twelve thirteen. They got married by the time I was fourteen, so they'd been together a year. That was in year nine, and yeah it would've been about fifteen sixteen. I mean Jacob groomed me from fifteen. I don't I don't remember being in year nine which was the [place name] house in being more than on his lap with an erection. That's the only level it had then the [place name] house. Erm but that's also when mum started telling me to wear nightdresses as well. Yeah, and it was after the [place name] when I was the coming in the shower, the line of shots, the undressing, and yeah that that sort of all started then. But then you know hugs that were just not right. Erm back then I knew that these weren't quite normal hugs. Erm you don't hug someone and stroke their back or get really close to their bottom. I mean I know that he was a tall man and I'm short, I mean this guy was nearly six foot, he'd have to really reach down to get to that level. It's not a natural place to be holding me there. For him that's really low, but that that happened so often you know that it sort of became and felt normal, and that meant that, and I think for me later on in life how that's affected me now is yes, I do like a hug and I can have a hug but yeah, and I'm always still suspicious of hugs. Erm and it hasn't thrown me completely off the idea of touch, but I'm now suspicious of touch if you know what I mean. I'm interpreting what that means because I don't know. I don't understand at the stages what touch means. Is it something that obviously boyfriend girlfriend touching, or is this just friend touching, or is this acquaintance touching? I don't, I I struggle with the interpreting because I feel now that what I had experienced growing up, as understanding what touch can be, or hugs can be, or smiles or kisses on cheeks, stuff like that. I don't trust the meanings of them anymore. I'm *constantly* suspicious I'm constantly questioning

them. So, I'm always reading body language at the moment because what I thought was true isn't true now, and it's hard, yeah does that make sense?

*Yes, it does.*

My memory, I, the thing that is in my memory that I have strongest is staring at that ceiling, and being still, and I mean still. I did say I'd be jumping timelines [laugh], that fear is what I still feel and remember to this day. It's something that sticks with me the most is that ceiling, and that *pumping* and that *weight*... And being still that's all I remember... I can't say, certain all the emotions going through because I have, I've got borderline personality disorder, so I struggle with regulating emotions and feeling them strongly, and I think that sometimes means that I misinterpret emotions. So, although BPD is affecting me now, I think it might've been caused back then and I've struggled throughout. So, although I can say that I've felt this emotion, I wouldn't know necessarily know what that emotion is or, if it was real, or if it's just my reaction to the memory of the emotion if you know what I mean?

*Elsie, you talk about borderline personality disorder and emotions, and I'm aware that you've recently had an autism diagnosis, so how does that relate to your emotions?*

I think that probably played a major part of me developing BPD because of not understanding these emotions and how to portray them, and not knowing in a healthy way to do so. Erm cus I did have in school, like I know I was really weird but I was like a superiority sort of complex. I always felt like I was better than everybody else because I had so much shit going on at home. I had so much bad stuff, but yeah, I'm still here, I'm still strong, I'm still obeying the rules, I'm still the head girl, I'm still doing all of this, I'm still, I mean I was the most unpopular head girl ever but that was because I was the teacher's pet [laugh]. Erm but I felt like I was better than

everyone as a result but yeah. I had to be within the rules and if somebody didn't do what they were supposed to do within the rules, it really upset me, but I couldn't understand why if you know what I mean. Like I couldn't understand why someone would [inaudible] happened all day, so we were doing these like new drills and stuff sort of thing, and so you had to walk within a particular line and something like that. There'd be people or girls that wouldn't do it and do something different, and it's one of the reasons I became unpopular because I would always keep telling people off, or no, you must do this, this way. You've gone off the line, you're in trouble you know, like that sort of thing. You've been told what to do, therefore you must do it the way you've been told, even though there are other ways to do some things, no you've been told do it that way, you must do it that way, yeah erm... Autism, emotions, how does that... I don't know... I'm I'm still learning the whole, trying to get used to the idea of them being separate, that one is an illness and one is the way of who I am because I've been told so much that the BPD is everything. That that is the root of my cause and all of my problems sorry, and layers of symptoms and everything, that I say is because of BPD, when my needy standards well you must do things in a particular way. My memory with directions, I could tell you erm road name by road name, when to change lanes and how to get to say [place name] or something. That this is just because I have not been able to er regulate my emotions that that the doctors my doctors kept bringing it back to BPD every single time. So, I'm now now finding it difficult to separate the two out, and say that that something that happened or experienced or the way I am is because of being autistic. Like is it because I don't want to be around people or care about people anymore? Or is that because erm of the autism? Or is it because of BPD? Or is it because of my experiences? Is it because of what happened to me, is that why I'm suspicious about

people I don't know? I'm struggling to separate everything out and everything makes sense. Erm when I have all of those questions, they felt like they were questions about *me as I am*, not about erm my emotional responses to things really like that. So that makes sense. Well this is the way I am so therefore, it must be on the spectrum but yet I present normal most of the time, if normal is the right word. I present as someone that does not appear to have any autistic traits whatsoever, but I've got so used to sort of hiding that. As soon as I step in erm er say the pub for example, as soon as I step into a social situation, straight away put on that role of smiley, happy, and please everyone, ask them questions about themselves. Sometimes I forget to do that though but you know show that interest, that fake interest when *actually I do not give a damn*. I do not want to know anything about a person. I will answer your questions if you ask me questions, that's fine I will do so, but I will not [laugh], I don't want to ask about how your day did. How you went to school, I I don't care [laugh] you know. It's just too boring, but yeah you have to pretend because that's how people are. You're supposed to to ask how a person's day is even if you don't want to know. Sorry.

No no. Don't apologise.

That's one of my main things. I do apologise for a lot of things. Sorry.

*It's ok Elsie. Going back to the rape.*

[Gasp].

*I'm sorry Elsie. It's ok for us not to go back there, I realise this is very painful for you.*

No, no. Yeah, yeah, it's painful but no I want to tell you all of it cus it was always the same fucking thing.

*The four rapes, was each experience the same?*

It was there was no change. He didn't suddenly change position or anything like that. I was, I would be in bed already asleep and he would come in, which means mum was asleep as well, oh my god..... That means she was there..... sorry [gasp]. Yeah, he he never changed it up, he he never changed routine. It was always the same.

Erm from what I remember there was no level of foreplay or anything like that either. There was nothing like that it was just go for it... Erm fuck did it hurt, but yeah... and I always stared at the ceiling... always didn't move, didn't do anything *but*... like I said to the police I... one of the reasons I'd taken so long to even make the decision to do this is because I didn't say anything, didn't do anything. That means it was ok. That means I gave consent, but I didn't want it to happen... And it never changed, it was always the same. But they weren't consecutive. It's not a case of the next day the next day. There was no rhyme or reason, no pattern to it. There was no like every month on the Tuesday. It was none of that. It was, it was completely random as to when it would happen. I couldn't tell you how many months it was apart, or how many days er it just happened.

*How was your relationship with Julian affected by your experiences of sexual abuse?*

So, me and Julian had tried at one point, he has his own issues, erm we tried, me and him. He was the reason we couldn't, Julian was the reason we couldn't. He's got problems with his penis. He still suffers with it today. Erm oh my god and erm so the time me and Julian did try er we were having a date night at the flat, and erm so er this was with the upstairs flat erm so we hadn't moved downstairs cus it was downstairs when Jacob did his thing. Erm so it was the upstairs me and Julian had the date night. Mum and Jacob weren't going to come back. Like cus I was cooking tea et cetera and it was the first time we were going to try you know. Erm

and they had to come home at the *wrong time* didn't they. So were just about attempting something me and Julian. Like we had the condom and everything and we were just about to sort of give it a go, and then we hear, because the upstairs flat it's got a downstairs first floor level entrance where the coats and everything is, and then you've got stairs that lead up to the flat so they'd come in at the downstairs. We were are like in a position so we move fast. I go off to do the tea. Julian goes to the toilet. Jacob comes in *full* on accusatory mode. Like attacks Julian and pushes Julian down the stairs, like pushing and pushing and pushing him down the stairs. Like you know Jacob was on full on protective mode of me, and mum was shouting and shouting, and I was shouting, and in the end erm although he was right we were trying to do something that's not for him. You know what I mean, so my tea was ruined, it got burnt cus I was cooking, so erm so mum made Jacob take us out for tea. We went to a lovely place and he wrote me a letter apologising for his behaviour, but that was really quite an impact on on Julian. Like Jacob is big, he's a big man, he's quite tall as well. Erm being pushed down these stairs that were spiral stairs as well, and it was quite a a thing. So, he already had that kind've protective reaction over over me, before he got to that level, before he done his thing... I I still can't really say it very well. I I still skirt round it...

*Can you tell me if your experiences with Jacob have affected your sex life with Julian, and if so how?*

It has all the way through. It still has issues erm we can't do certain things because it just especially the the missionary, the lying the lying on top, that's the one I struggle with the most because Julian can't keep his weight up because he hasn't got any upper body strength, and although I can be fine fine and happy, and it is Julian, it's not Jacob it's Julian, and and god it really gets me when someone calls Julian,

Jacob. It really gets me. Why do they both have to be both J's? [laugh]. Yeah, yeah it's Julian erm yeah erm so everything will be fine, and I'm convincing myself, and I'm there in the moment with two of us but as soon as he puts that weight down I lose it. But yeah again I still have to please Julian so I keep it going for his sake only. Erm encouraging him to finish so that he can be done with quickly and be fine. Erm yeah, we struggled two of us, particularly for a couple of years. It wasn't really until like half way through first year at uni that we were able to have fully something going on yeah. So yeah now we struggle. So, our sex life since then is is always an issue erm, and the first year you know we'd been together a year before I went to off uni, and so a year and a half before into a relationship before we could actually do that. We obviously had the whole kissing and hand holding. Er er fingering was allowed and stuff like that but was never really able to to go much further. Julian is so different, he's so, he's Julian... so sweet.

*How have you coped through all of this Elsie?*

Didn't cope. I had erm, sixteen and seventeen were very bad years for me. Erm I would attempt to have some sort of level therapy course when come to broach that subject because that's where therapists seem to see that my emotional state stems from what had happened to me, and I have to address it in order to get better. I couldn't cope with it so I self-harmed. I have erm scars on here which you can't really see in this light but there's one particular there. They go all the way along and I have them on my legs as well. I would cut. Erm I had a couple of suicide attempts. Erm dropped Julian me off at a gig to go to [place name] one night, on the way back er I don't know what it was that triggered me, something had triggered it, like a memory cus after once I'd started letting all, letting it all come through, and actually acknowledging that this had happened to me because I got through uni with being

fine you know. I'm good, I'm strong, nothing happened, nothing happened and just literally forgot about it, put it in the back of my mind and just got on, but letting it come through like that meant that I was having flashbacks every now and then. They were worse when I got drunk because I sort of lost inhibitions, and I'd end up in hospital because I would've done a serious car jump or I used to crash not crash I used to jump in front of cars and the police would get involved and sort of sit with me and stuff. Erm and the other was that one time I tried to crash my car erm and the doctor took the keys off me. He didn't do the official er take my licence away sort of thing but he basically said you are not to have any access to the car, and that happened for six months, and then I had an assessment with him and because I'd changed my method of suicidal attempts, it became more overdoses that erm I was allowed to have the car back.

*So how many times did you attempt to take your own life?*

In the hospital three times but attempts to actually do it and sometimes fail.

Sometimes it would be a case of like I'd have the pills all lined up, or like I would be driving and yeah all of those, or even those jumps in front of the car, all of those attempts, or thoughts or planning's, they would happen. I mean the planning would start to happen at least once a week where I would have it all lined up, or I would have written out what I'd do so if I go to this particular bridge at this particular time and stuff like that. Those thoughts and those things, they would happen at least once a week. Erm every two three weeks I would've done something. Sometimes the taking of say erm cus I was on sertraline, Julian was on sertraline. I was also on er propanolamine for anxiety. Julian had amitriptyline in the house which is what messes your heart up so if you have propanolamine and amitriptyline together one is trying to speed your heart up the other is trying to slow it down. So, I wouldn't

necessarily of of got very far. I might've maybe taken three tablets of each or something like that but then cus I struggle to swallow pills, and then that would sort of make an issue so I wouldn't get any further. Erm there would be times where I've gone through enough of it where we'd call the doctor, the hospital, and they would say ok she does need to come in to be monitored especially with the Amitriptyline and the Propanolamine, that was the one they were always worried about. Er Julian had to be in control of my medication. Erm I was only ever given a month's supply at a time which was the most expensive way for me because Julian was getting six months Sertraline at a time costing him only eight pounds sixty a time. I was getting mine costing me eight pounds sixty a time every month so god it got ridiculously expensive, but he had to be in control. Like erm the doctor put a stipulation on mine, on my thingy, that only Julian could pick it up and he had to be in control of it, but he wouldn't very good at hiding it. I'd always find it somewhere. At one point he kept leaving it in the car, but yet the keys would still be in the car. When I'm desperate, in that mode, I'd find them and that happened erm for the best part of 2017. I was suffering really badly with those erm [inaudible]. My friend Lucy, she er at one-point erm she wanted to go back to work, she'd quit her job but she, her and her husband agreed that she can't go back to work just yet because I was too fragile. Erm if I was left alone I did stuff, I would cut, I would plan, I would get upset, I'd be found in my bedroom crying and stuff like that. I was highly emotional, but yeah if she was with me and we were just playing on a game or just watching tv I was fine. I was ok erm, but she's back at work now and I'm a lot stronger.

*Do you think you can recover from sexual abuse, and if so, how?*

Having reported it to the police I felt is the first step of the recovery. Like as I said I was trying erm because I'd gone to AXESS in [place name] which is an organisation

that deals specifically with women, and they can do men as well but primarily women who have suffered sexual abuse or any form including historical childhood rape et cetera. Erm and they specialise in trying to recover from that to help you through it. But I'd had eight sessions with them and we realised that it was just wasn't going anywhere because it was affecting me. Like I was getting, erm the cutting was amping up but every time following a session it would always result in something like that. I realised that I wasn't going to get any better without having gone to the police because it was always going to be looming on me that he's still out there. The guy remarried who was with a woman who has a son with [genetic syndrome]. She runs a [place name] for adults and children with [genetic syndrome], and he's the manager of the [place name]. Erm we only found this information out because I'd told my dad. He'd hunted Jacob down and he'd made it known, he told me that, he's running a school for [genetic syndrome]. There are people that are vulnerable, more vulnerable obviously than I was, and he has access to people. Then I felt that guilt *that I have to do something* because, I didn't want to. *God did I not want to*. I did not want to bring it up. I had not to that day because I had not actually said to anybody, I implied, constantly implied, and let them fill in the gaps. I had not said to anybody exactly what had happened. I didn't want to go that way but I wasn't going to get better and heal with that hanging over my head that he's still out there. He got away with it. I failed my sister... Maybe there's someone else out there that I could not fail, if you know what I mean. I felt like I created a fictional person that by going to the police I'll save them, you know that there is someone else out there I can save. I thought I'd saved my sister but we haven't talked about it. I kind've don't think I'm strong enough to ask her exactly what happened. I can't do that. It gets me even now to know that I've failed [crying] but to the extent that I *failed*. I don't want to

know... I never in my eyes saw Jacob do anything inappropriate like he was doing with me you know. I never saw anything so I didn't fully myself believe that. I felt that Gemma might've jumped the gun you know. Maybe maybe it was the fact that she'd saw Jacob be like that with me, but Gemma, I swear that what Gemma had gone to the police about her, but I had never seen anything to warrant that. I didn't feel like my sister was in danger you know. I felt like I was guarding, protecting her you know, keeping his attention on me meant that she was safe... But I can't no, I won't ask her what she went through. She will've told the police as well and I suppose if and if it went to the court, and it was still a big if, then it might've got found out then cus Gemma's original report although he can't be charged, it was going to be taken as evidence being included in some way. I don't know what it was cus I don't I don't ask that many questions about it because it makes it more real if you know what I mean. Er ACCESS do have another erm organisation which is ISVA Independent Sexual Violence Advisor's. They deal with anything that I had to deal with with the police so they came with me to the video report. Erm they answer questions about er what's going to happen. They would also be with me if it went to court. They'd be there as my advocate making that sure my rights were being respected. Erm and being that person that can support me basically without it being family because I'll be very very emotional and when I had to do the video evidence it was nice having someone that I trusted, yet she wasn't allowed to know anything. She wasn't allowed to watch the videos. She's not allowed to know anything, the ins and outs of what happened because she's just there to be impartial to make sure that I'm taken care of and that my rights are being reserved and what have you but yeah. When I had to have a break in the middle of that interview, it was nice to have her to hold on to, to have a cuddle and a hug, because she was strong. She didn't cry with me you know she just

talked me through it. So, this is what's happened so far. She put that practical sense in it and that's what I needed cus I'm cus I'm a particularly organised and practical person and that helped me get better and get back on it when she put structure in place for me, and that felt good.

*What was the disclosure process like for you?*

Erm so I had to make a phone call first to say I want to report a historical erm sexual abuse situation on the phone. Then they got a police officer in [place name] erm to er speak to me so a phone call first. Then I had to go into the station and talk to her. It was [police officer's name] and another erm woman erm and they've did like a written sort of statement like a preliminary, and she said then that it must've felt good for me because the way that I just bluffed out this story, and it wouldn't have been that that much different to the way that I've talked today, kind've like tried to fill in gaps, set scenes et cetera cus obviously drama, setting scenes is one of those type of backgrounds for me. It just feels natural but it did like pretty much just like released it all... And it did kind've [sigh]... Not feel good but as if like a pound or so off my weight and shoulders had just sort of gone because not only had I finally taken that step with the police, going down the route of getting a prosecution and once you make that step *it's a big deal*, and it's all a he said she said situation. So, it's er the police officer that I'd dealt with in [place name] in erm [place name] cus I had to be sent to [place name]. He said that the strength of this case was lying *solely* on my video evidence and how believable I was, and again it's I can't lie very well, so that had to be truthful and honest, and it was. I mean who could create this kind've shit, who could lie about that, you know... But then yes, it felt like I'd lost a little bit of weight and it felt good and relieved in that sort of sense, and I'm being believed here, but with it er was a greater weight because I was actually having to deal with the

police and their systems, and the responsibility that came with it such as erm the interviews. Er because obviously Jacob was being arrested, released, arrested, released, every time they'd find something new or they kept arresting, releasing him. It was like the gravity of it all that really hit home after that first written statement. That was the point of no return. I can't sort of now say no, but I'm not doing this now, I can't do this now, it's like I've made that step now, I have to do this. I have to be strong, I have to survive, I have to do this and that's how I see it. I'm surviving, I'm getting through it. Each day is a survival, it's its little miracles little little erm wins each time.

*How do you think the criminal justice system or support services could be improved?*

[Sigh] Erm the experience I've had with the [support services name] they kept obviously saying that we can't help you feel better about what happened to you. We can't er obviously make it go away. All we can do is just erm you know help you in what way we can without it being anywhere like near therapy, cus I understand that they are not therapists what have you, but I'd just had a situation where I've divulged everything that went through with me to the police, and then I'm left to leave that building as someone who's vulnerable, especially with the mental health condition that I have. I already have a track record with suicide and self-harm. To just be left to go and do it yourself and they say oh [support services name] will help you, but all [support services name] will do was give me a booklet on er how to sleep better because I was having nightmares. But yet what I needed to do was to talk it through with someone like like a therapist sort of situation to make me feel better about it, where someone can hold my hand and tell me it's ok and let me divulge it because I had a couple of meetings with [support services name] and it was like, it was always a case I couldn't talk about it, what happened, I couldn't say what I'd gone through. I

had to be constantly mindful of trying to stop it from appearing like a therapy session, and sometimes all therapy is is just one person talking and the other person listening, and that was all I needed

*That was all you needed?*

Yeah.

*Did you get that?*

No. Because erm er ACCESS erm they had to stop therapy because erm they had to give over all of their notes and everything to the police because apparently Jacob's lawyer could say that erm therapists had coached me into what to say. Erm creating false memories etc. Er the same goes for when I'm constantly kept trying to going back to secure mental health teams to try and get some help because I was struggling with my everyday things like leaving the house, go to do shopping, erm being in public. Erm I mean some of that probably is actually because of the autism but like I needed, I needed help and they were constantly kept taking me off the waiting list saying actually no we can't do this because of your court case on-going and they wouldn't want to lose their jobs because again, if something they do or say is seen as leading or coaching or what have you, even if I was saying ok I don't mind dealing with the trauma side ok, I know we can't do that can we get some help from any of the others, with my suicidal tendencies self-harm with being able to go out out erm, put some plans in place or help support me in in other ways but, I kept getting told no, because of the risk of affecting the court case

*Can you explain what it was like having to repeat your experiences to different people, services?*

I hated having to tell the story over again because it meant I had to keep repeating it and *it's not nice* saying something over and over again, and I mean that first couple

of months I could never get out of it. I was constantly reliving it, re-feeling it, and it was bad enough that the year before I'd had those flashbacks and I was having the nightmares and the results that that come to and, yes, I had a strong period I hadn't hurt myself in a while and that's why I agreed to go to the police when I did at that time because I was being stronger. Every time I had to tell my story to them which was admittedly only three times, so that first initial one then I had the interview and then I had to tell it again to [name place] police when they it took over they kept wanting to ask me loads more questions. I don't know why but yeah, and it just kept bringing it constantly to the forefront. It was as if it was happening all over again in my mind because I'd just lie, and that was the thing that constantly kept upsetting me and bringing it back was *why didn't I do anything*, why didn't I scream or push now that I realised that my mother was fucking there, but why didn't I do anything, and that's the thing, that was the worst thing to me to kept having to repeat it. I kept doubting myself more and more and more that actually I'm wrong about the situation, and that there isn't anything here that the police can do. There's isn't a crime to be reported, and that the more and more, I the more and more I get found out that actually no Elsie, you were compliant, you were consensual, that's fine there's nothing more that can be done, and I would've put myself through that feelings and emotions *all over* again, for nothing, you know what I mean.

*What sex education did you receive at school?*

Primary school they did that whole see through image of a penis and a vagina thing which was just nothing. Erm the first time I had, nope nope er there was nothing like, it was crap sex education [laugh]. Like to me I feel hopefully and I think it's better that sex education should be more of actual sex education, because, otherwise, people are just going to constantly keep learning about it from online, and porn, and tv

programmes and that is not what sex is about, so therefore, we are all going to be comparing ourselves to that, and it's horrible, and schools aren't helping with them with them just doing that science book of erm, a man lying on top of the woman and the see through image of a penis and a vagina and saying he goes in there he ejaculates she releases, er er eggs etc yes that's good to know, but the *how*, is the other thing that needs to be taught, and I didn't have any of that

*What would you recommend for good sex education programmes within for young people at school?*

Not in primary school, I'd say when they reach sixteen which is the legal age that kids can have sex. I think that's the time to start arming and preparing themselves because as much as you can say that someone, erm that a man lies on top of a woman he puts his penis in and he moves and then he, that's not, what's going to teach them, I would say around sixteen, that, cus in my school we had things called citizenship and you did that all the way through school, and that was like erm, and that that subject is when I think it would be better to talk about it I mean teenagers, they're going to struggle anyway, about it, and yes elective you know choice do you want to take it or not. Erm maybe not in a whole group situation because that's going to be one heck of an embarrassing situation, and that's just going to cause more bullying and be uncomfortable and no one's going to like to do that, but having it as an option that you can go erm throughout the year, one kid at a time say goes and has er er a particular teacher and they go and learn about you know what it's like to have sex erm, how that's going to be. I was just thinking more around the lines of videos and books and stuff but showing things that are good cus we did never sort of, I don't remember ever seeing an actual photo of er erm a vaginal area. It was all drawings in school books. We had no idea to know what was normal and natural and

to rely on our parents to tell us that these sorts of things, it's not necessarily going to be reliable and happen and it causes more, issues for people and it creates that situation where people, er men and women can be vulnerable without actually needing to be, it's not necessary if you know what I mean... I like what that school in Birmingham is doing with the, erm, er other families, that you know the curriculum that they're doing. I like that because I think it will reduce bullying later on. It might take a couple of generations or two for it to be normalised, but it will reduce bullying later on cus there are two mummies, there are two daddies, there are mummies that are now daddies, and I think that just needs to be normalised, so that it may take a take a couple of normalised and reduced generations but, when it comes to high school, no-one is ever going to get bullied, for coming out as being gay. I got it so *bad* cus I found out that I was bisexual in high school, and I got it bad, and I was in a school that had no minorities we had *no* ethnicities at all. Er there was no Asian, no no one was black either, no one, just one sort and this was a big high school as well. No one ever came out as gay and I was the first person to sort of say to my friends which I shouldn't have done because obviously, they weren't obviously friends to say that I think I'm bisexual, I think I like women as well. I got this whole how's your bicycle Elsie and stuff like that, but I want that normalised and reduced.

*What kind of sex do you enjoy?*

Obviously being an adult, I do like watching porn. I don't like the standard vanilla sex acts sort of porn watching, I do go down the more erm not BDSM bondage I suppose erm, but more female control orientated, that's where I kind've go. I want to keep porn separate from actually is, love making you know.

*Elsie, you've told me your story of sexual abuse and I thank you. I appreciate that it has been painful for you, but the data you have given me is extremely useful and you've answered all of the questions I'd hoped to ask you. Thank you.*

But is it really because I'm worried, I'm thinking in my head that is not exactly somebody, that's somebody, that's gone through a situation that I've gone through sexual abuse that's not telling me?

*Please do not be worried Elsie. You've articulated your story very effectively and the information you've given me will help other survivors of sexual abuse. Thank you for your courage in disclosing your lived experiences.*

Thank you for giving me the the opportunity to participate in this research. It has has yeah helped me, yeah to be able to tell you all of my story and I I hope it will be of of benefit to other people.

*You are very welcome Elsie and I thank you once again. Is there anything else you'd like to ask me?*

No.

*Ok. As discussed earlier, we will have a de-brief. Would you like to have a break now? Or do you want to continue and have a debrief now?*

I will have the debrief now.

*Ok, that's fine.*

## APPENDIX VI

### EXAMPLE OF EMERGENT THEMES

Refer to chapter 3 which provides a reminder of the coding process.

**Table of emergent themes**

Exploratory notes/initial coding	Interviewer	Interviewee	Emergent themes
<p><u>Confusion regarding autism and emotions.</u></p> <p><u>A marked effect or influence of diagnosis?</u></p> <p><u>Is she establishing her own sense of self/identity or is she trying to conform/fit into what she has been told about BPD?</u> It's the language of having something imposed upon her.</p> <p><i>Apologising.</i></p> <p><u>This seems important, she has been 'told stuff' that doesn't reflect her experience or adequately describe her.</u></p> <p>In order to be able to fit into the "norm".</p>		<p>autism emotions how does that... I don't know... I'm still learning the whole, trying to get used to the idea of them being separate, that one is an illness and one is the way of who I am, because I've been told so much that, the BPD is everything, that, that is the root of my cause and all of my problems sorry and layers of symptoms and everything that I, say is because of BPD when, my needy standards well you must do things in a particular way, and my memory with directions I could tell you, erm road name by road name when to change lanes and how to get to say [place name] or something, that</p>	<p>Conflict between autism/emotions. Confusion.</p> <p>Establishing sense of self/identity Who am I?</p>

<p>Diagnostic overshadowing?</p> <p><i>Repetitive use of the term 'is it because' and she appears confused as to who she really is and is questioning if it is associated with her different diagnoses or her experiences and is trying to establish a sense of self/identity. <u>She is experiencing difficulty in trying to make sense out of everything being separate.</u></i></p> <p>This is interesting! CAN they be distinctly separated? Is this her problem or does it relate to problems around the labels we assign people and how they are used?</p> <p><i>'me as I am' - emphasised authenticity?</i></p>		<p>this is just because I have not been able to regulate my emotions that that the doctors my doctors kept bringing it back to, BPD every single time, yet so I'm now now finding it difficult to separate the two out, and say that, that something that happened or experienced or the way I am is because of being autistic, like is it because I don't want to be around people or care about people anymore or is that because, erm of the autism or is it because of BPD or is it because of my experiences, is it because of what happened to me is that why I'm suspicious about people I, don't know I'm struggling to separate everything out and everything makes sense, erm when I have all of those questions, they felt like they were questions about <i>me as I am</i>, not about erm, my</p>	<p>Establishing sense of self/identity</p> <p>Confusion/questioning oneself</p> <p>Confusion/questioning autism</p> <p>Confusion/questioning BPD</p> <p>Confusion/questioning experiences</p> <p>Confusion</p> <p>Sense of self/identity</p> <p>Sense of self/identity</p>
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<p>Identifying as being on the autism spectrum and acknowledges that in general she appears to be 'normal' but she has worked at hiding her autistic behaviour which could be as a result of masking.</p> <p>Playing a role. Masking in regards to a non-autistic person.</p> <p><i>'fake interest' – mask? Use of language emphasises that actually she doesn't give a damn and is masking her authentic self in order to fit in.</i></p>		<p>emotional responses to things really like that, so that makes sense well this is the way I am so therefore, it must be on the spectrum but yet, I present normal, most of the time, if normal is the right word, I present as someone that does not appear to have any autistic traits whatsoever, but I've got so used to sort of hiding that, as soon as I step in erm, er say the pub for example as soon as I step into a social situation straight away put on that role, of smiley happy and please everyone ask them questions about themselves, sometimes I forget to do that though but you know show that interest that fake interest when <i>actually I do not give a damn</i>, I do not want to know anything about a person, I will answer your questions if you ask me questions that's fine I will do so, but I will not</p>	<p>Masking/pretending to be normal</p> <p>Masking</p> <p>Masking</p> <p>Masking/pretending to be normal</p>
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<p>Pretending to be normal and has acquired the skill of being able to mask her authentic self and has learnt how to conform to the conventional societal norms.</p> <p><i>Apologising.</i></p> <p>Recognition that apologising is pivotal in relation to what she does. <i>Apologising.</i> As I said the word 'rape' she gasped in shock.</p> <p><i>Use of the word 'fucking' emphasised anger.</i></p> <p>Stark realisation/shock that her mum was present when she had been raped by her step-dad.</p> <p><i>Emphasised the word "was" and gasped for</i></p>	<p>Going back to the</p> <p>No no don't apologise</p> <p>Going back to the rape</p> <p>The four rapes, was each experience the same</p>	<p>[laugh] I don't want to, ask about how your day did how you went to school I I don't care [laugh] you know, it's just too boring, but yeh you have to, pretend, because that's how people are you're supposed to, supposed ask how a person's day is even if you don't want to know</p> <p>Sorry</p> <p>That's one of my main things its I do apologise for a lot of things sorry</p> <p>[GASP]</p> <p>It was always the same fucking thing, it was there was no change he didn't suddenly change position or anything like that I was I would be in bed, already asleep and he would come in, which means mum was asleep</p>	<p>Masking/pretending to be normal</p> <p>Repetition of the word "sorry" - is this an indication that she is apologising for her pain even though she wasn't the cause of it?</p>
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<i>breath at the reality - and then apologises.</i>		as well, oh my god... that means she was there... sorry [gasp]	
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